

'Is knowing that you have rights enough?'

Exploring Marginalised Women's
Awareness, Understanding and Practice of The Right to Health

Jacky Thomas

THMJAC002

A dissertation submitted in partial fulfillment of the requirements
for the award of the degree of
Master of Philosophy

Faculty of the Humanities

University of Cape Town

December 2009

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This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

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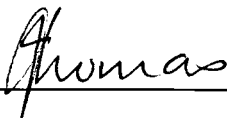
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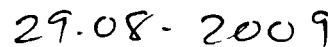
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OF THE RIGHT TO HEALTH**

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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
IIZ/DVV	Institute for International Cooperation of the German Adult Education Association
CSO	Civil Society Organisation
EQUINET	Regional Network for Equity in Health in Southern Africa
HIV	Human Immunodeficiency Virus
HSRC	Human Science Research Council
ICESCR	International Covenant on Social, Economic and Cultural Rights
ILRIG	International Labour Research and Information Group
SALFS	South African Labour Force Survey
MDGs	Millenium Development Goals
NGOs	Non-Governmental Organisations
NMF	Nelson Mandela Foundation
PHM	People's Health Movement
RAG	Resource Action Group
SA	South Africa
SAHRC	South African Human Rights Commission
TB	Tuberculosis
TV	Television

TWC	The Women's Circle
UCT	University of Cape Town
UDHR	Universal Declaration of Human Rights
UNHCHR	United Nations High Commission for Human Rights
WHO	World Health Organisation

University of Cape Town

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Jacky Thomas

December 2009

ABSTRACT

This research study explores women's awareness, understanding and practice of their rights to health. The target group in the case study is women. These women live in townships and informal settlements in Cape Town and are part of a community-based network called The Women's Circle (TWC).

The purpose of this study is to advance understandings or bring out contradictions in current theoretical debates in relation to health and human rights. Primarily the study aims:

- To generate knowledge which could assist in strengthening the TWC women's capacities to invoke their rights to health, access health and healthcare and improve the quality of their lives;
- To identify whether the different theories of adult education can inform the work of the University of Cape Town (UCT) Health and Human Rights Unit, which is currently developing learning programmes around the right to health for civil society organisations; and
- To gather empirical evidence to assist TWC in strengthening partnerships with the state and lobbying government around ensuring access to health rights and services.

This study is inter-disciplinary and links adult education to health and human rights. Therefore the literature review draws on work of authors within the following domains: Nefdt (2003) in social services; Sen (1990) in development; London (2004); Ngwenya (2000) and Mann, Gruskin, Grodin and Annas (1999) in health and human rights.

Furthermore, to analyse the women's learning the theoretical framework draws on literature in the field of adult education which include the Situated Learning theorists (Lave and Wenger, 1991), Phenomenological (Fenwick, 2001), (Mezirow, 1994) and Radical Feminist Pedagogy Ismail (2006); Walters (1998) and Weiler (1991) perspectives which provide theories that have direct relevance to this study in terms of the site of practice and its conceptions of learning and teaching.

These perspectives enabled the study to understand and analyse the influence of women's histories and socio-economic factors and relate it to women's learning in informal contexts

This is a qualitative study, therefore data was collected through in-depth interviews. The analysis generated themes which illuminated a complex interaction between and amongst personal, socio-economic and institutional factors, which both enhance and detract from these women's experiences of their health rights.

The findings to date indicate that lack of information is partly why many TWC women are frustrated, despondent and unable to assert their rights to health, particularly when visiting public healthcare institutions. These women's lack of access to health and healthcare is compounded by lack of knowledge as well as embedded power relations within the contexts these women operate in. There is value in women's learning in informal sites such as TWC. Informal and non-formal learning processes can assist and enable women to experience increased positive self-images and build knowledge in relation to health rights. These can translate into transformations in perspectives and can lead to a sense of empowerment, which often results in women taking action.

The study concludes that exploring the context within which vulnerable women learn will enhance our understanding of the gap between awareness creation, understanding and practice in relation to health rights.

CONTENTS

	Page No.
Acronyms and Abbreviations	iii
Acknowledgements	v
Abstract	vi
CHAPTER 1: OVERVIEW OF THE STUDY	1 - 16
INTRODUCTION	1
1. BACKGROUND	1
1.1. South Africa and International Human Rights Law	1
1.2. South African Constitutional Framework	3
1.3. Legislative and Programmatic Reform	5
1.4. The South African Human Rights Commission	6
2. STUDY CONTEXT	6
2.1. TWCs Way of Working	8
2.2. Governance	10
3. RESEARCH MOTIVATION	10
4. PROBLEM STATEMENT	11
5. PURPOSE OF THE STUDY	12
6. AIMS AND OBJECTIVES	13
7. RESEARCH QUESTION	13
8. THEORETICAL FRAMEWORK	14
9. RESEARCH METHODOLOGY	14
10. OUTLINE OF THE STUDY	15
CHAPTER 2: LITERATURE REVIEW	17 - 36
INTRODUCTION	17
1. CONCEPT CLARIFICATION	17
2. HEALTH AND HUMAN RIGHTS PERSPECTIVES	19
2.1. Human Rights	20

2.2. Health and Human Rights	20
3. WOMEN'S VULNERABILITY IN SOUTH AFRICA	21
3.1. In Relation to Health Rights	23
4. POSSIBILITIES AND CONSTRAINTS	25
4.1. The Patients' Rights Charter	25
4.2. The South African Constitution	26
5. WOMEN'S LEARNING WITHIN A CIVIL SOCIETY CONTEXT	28
5.1. Learning as a Group: Situated Learning Theorists	29
5.2. Learning as Individuals: Perspective Transformation	30
5.3. The Impact of Power Relations on Women's Learning: The Radical Feminists	31
5.5. Reciprocal Relationship between Individual and Group Learning	33
CONCLUSION	34
CHAPTER 3: RESEARCH STRATEGY AND METHODS	37 - 45
1. RESEARCH DESIGN	37
1.2. Research Methods	38
2. SCOPE OF THE STUDY	38
3. SAMPLING AND SELECTION OF PARTICIPANTS	39
4. DATA COLLECTION	40
5. DATA ANALYSIS	41
4.1. Validity and Reliability	42
4.2. Ethical Considerations	44
4.3. Methodological Challenges	44
CONCLUSION	45
CHAPTER 4: PRESENTATION OF THE FINDINGS	46 – 79
INTRODUCTION	46
1. PARTICIPANTS' PROFILES, LIFE EXPERIENCES AND SOCIO- ECONOMIC CONTEXTS	47
1.1. Participants' Profiles	47

1.2. Participants' Life Experiences	49
1.3. Analyzing the Profiles	52
2. LEVELS OF AWARENESS, UNDERSTANDING AND PRACTICE OF HEALTH RIGHTS	54
2.1. How Women Learn about their Rights	54
2.2. How Women Feel about their Rights	57
2.3. Women's Interpretations of Human Rights	58
2.4. Women's Interpretations of their Rights to Health	59
2.5. Women's Views on the State's Role in Promoting Health Rights	60
3. FACTORS WITHIN TWC WHICH ENABLE AWARENESS, UNDERSTANDING AND PRACTICE OF HEALTH RIGHTS	62
3.1. Motivations for Becoming and Remaining Part of TWC	62
3.2. Experiences of TWC	63
4. BARRIERS TO AWARENESS, UNDERSTANDING AND PRACTICE OF HEALTH RIGHTS	68
5.1. In Relation to TWC	68
5.2. Within the Context of Public Healthcare Institutions	71
CHAPTER 5: DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS	78 - 91
INTRODUCTION	78
1. OVERVIEW OF FINDINGS: AWARENESS, UNDERSTANDING AND PRACTICE OF HEALTH RIGHTS	78
2. DISCUSSION OF THE FINDINGS	78
2.1. Women's Histories, Life Experiences and Socio-Economic Contexts	79
2.2. The Impact of Socio-Economic Factors	80
2.3. How Socio-Economic Influence Women's Motivations to Learn	81
2.4. Women's Experiences within TWC	82
2.5. The Impact of Women's Histories on Learning in TWC	85
2.6. The Impact of Women's Histories on Learning in Public	86

Healthcare Contexts	
3. CONCLUSIONS	89
4. RECOMMENDATIONS FOR FURTHER RESEARCH	91
REFERENCES	92
APPENDICES	
Appendix A: Interview Guide	
Appendix B: Copy of Blank Consent Form	
Appendix C: TWC Brochure	
LIST OF TABLES	
Chapter One	
Table 1: Key international and regional treaties on human rights ratified by South Africa	2
Chapter Four	
Table 2: Profile of participants	48

CHAPTER 1: OVERVIEW OF THE STUDY

*"What will this world become if you don't have rights?
You will feel that you are in prison"*

(Bulelwa quoted on p 56)

INTRODUCTION

This is a qualitative research study. The target group is part of The Women's Circle (TWC), a community-based network of women in Cape Town. TWC aims to provide access to information, opportunities and resources for women coming from low income communities in Cape Town.

This study is not an evaluation of TWC and does not seek to make generalisations to other members of TWC but seeks to explore eight women's awareness, understanding and practice of their rights to health.

1. BACKGROUND

1.1. South Africa and International Human Rights Law

In 1946, The World Health Organisation (WHO) declared health a human right in the preamble to the WHO Constitution (WHO, 1946). Notably, the right to health is all encompassing, protecting not only the right of access to healthcare but also the socio-economic determinants of health. Yet, in many developing countries like South Africa (SA), people's health and access to healthcare continue to deteriorate (London, 2004).

Importantly, international human rights laws have created possibilities to action health rights. For example, The United Nations International Covenant on Social, Economic and Cultural Rights (UN ICESCR, 1976 Article 12.1)¹ spells out

...the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

To attain this, states should minimally take all measures regarded as necessary to provide for the healthy development of citizens. These include creating conditions which guarantee health services in the event of illness or disease.

¹ http://www.unhchr.ch/html/menu3/b/a_ceschr.htm

Additionally, the UN pronounced a General Comment 14² during August 2000, which explains states' core obligations in relation to health, emphasising availability, accessibility, acceptability and quality of healthcare as vital fundamentals of the right to health.

General Comment 14 expresses the right to health as

an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as access to safe and portable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health.

Furthermore, South Africa has ratified nine of the fourteen key international and regional treaties and optional protocols³ on human rights.

Table 1: Key International and Regional Human Rights Treaties Ratified by South Africa

	Instrument	Ratification
1.	The International Convention on the Protection of the rights of all Migrant Workers and Members of their Families	16/7/95
2.	Convention against Torture and Other Cruel, Inhuman and Degrading Treatment or Punishment	14/1/96
3.	African Charter on Human and Peoples' Rights	9/7/96
4.	Convention on the Prevention and Punishment of the crime of Genocide	10/12/98
5.	Convention on the elimination of all forms of Discrimination against Women	9/1/99
6.	Convention on the rights of the child	9/1/99
7.	The International Convention on the elimination of all forms of race discrimination	10/3/99
8.	African Charter on the Rights and welfare of the Child	7/1/00
9.	Convention on the Prohibition and Immediate Action for the Elimination of the worst Forms of Child Labour	7/6/00

Yet, South Africa has not ratified the ICESCR though the country is a signatory to the ICESCR since 1994 because when a country ratifies a UN covenant, it becomes legally binding within the country. Thus, by ratifying the ICESCR the state would be obligated to realise the all-encompassing definition of health.

² [http://www.unhchr.ch/tbs/doc.nsf/\(symbol\)/E.C.12.2000.4.En?OpenDocument](http://www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En?OpenDocument).

³ Kamupira, M. London, L. (2005) Health and Human Rights Division Southern Africa. Equinet Policy Discussion Paper 25. June 2005, pg 16.

1.2. South African Constitutional Framework

The 27th April 1994 marked a major shift in South Africa's history. The first, free, national election was held, heralding the end of the Apartheid state and the beginning of a transition to democracy. One of the new government's priorities was to ensure a human rights-based and gender-sensitive Constitution, including political, civil and comprehensive socio-economic rights. This comprehensive inclusion of socio-economic rights as enforceable rights in the Constitution is a world first (Albertyn, 2006:195) and remains the foundation for all laws in South Africa.

Rights to health⁴, enshrined in the South African Constitution (Act 108 of 1996), closely follow the rights and freedoms protected under the Universal Declaration of Human Rights⁵ (UDHR, 1946), which views health as one of a range of socio-economic rights, all interdependent, indivisible and essential for people's well-being and development. As indicated, these are substantive rights, which protect not only the right of access to healthcare but also the socio-economic determinants of health, giving concrete expression to the state's firm commitment to *promote, respect, protect and fulfil* socio-economic rights, particularly health rights (Section 7(2), Act 108 of 1996).

The South African Constitution, regarded as one of the most progressive in the world, includes the promotion of human rights. This is a state mandate particular to the South African Constitution and creates an obligation on the state to educate people to help them realise their health rights. Importantly, the Constitution provides for citizens to draw on international law like the ICESCR even if unratified by the country.

⁴ Under the Constitution the following socio-economic determinants of health are protected:

- a) The right to education: Section 29
- b) The right to healthcare: Section 27
- c) The right to food: Section 27(1)(b), 28(11)(c) and 35(2)(e)
- d) The right to land: Section 25
- e) The right to water: Section 27(1)(b)
- f) The right to an environment not harmful to your health: Section 24
- g) The right to social security: Section 27(1)(c) and section 28(1)(c) of
- h) The right to basic social services: Section 28(1)(c)
- i) The right to housing: Section 26, 28(1)(c) and 35(2)(e)

⁵ www.unhcr.org/ref/udhr/lang/eng.htm

However, the Constitution must do so as resources become available within the country. Section 27 (2) of the Constitution enshrines the state's obligation in relation to a number of socio-economic rights:

The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.

The concept of *progressive realisation* includes overcoming implementation challenges to providing minimum essential levels of health and healthcare, and having a plan to maximize the rate of ensuring progressive realisation of health rights. It is therefore accepted that this progression should take place as a country becomes more able to attain a higher standard of health which provides scope to advance health rights (Mann et al., 1999).

Internationally, the Constitutional Court of South Africa has been recognised for setting legal precedents in terms of the justiciability of socio-economic rights, particularly for marginalised groups. In the *Minister of Health and Others v Treatment Action Campaign and Others (No 2)* 2002 (5) SA 721 (CC),⁶ the court ruled that mothers have a right to access drugs for the prevention of mother to child transmission of HIV.

However, the concept of progressive realisation also effectively limits socio-economic rights to the bare essential minimum a state is able to provide at a given time (Gruskin et al., 2005). For example, in *Government of the Republic of South Africa and Others v Grootboom and Others* 2001 (1) SA 46 (CC)⁷ the court ruled that homeless people have a right of access to shelter and subsequently prevented their removal from private land.

In both the above cases, by ruling in favour of marginalised groups, the Constitutional Court sent a clear message that the state has a legal obligation to ensure vulnerable groups are not left destitute or disregarded. Secondly, the state and courts have joint responsibility to ensure consideration for people living under such dire circumstances (London, 2004).

⁶ www.saflii.org/za/cases/ZACC/2002/15.html

⁷ www.lrc.org.za/docs/judgments/grootboom_cc.pdf

Despite the Constitutional Court ruling signifying the justiciability of socio-economic rights and the successes and gains made in existing policy and legislation, implementation of these rights, particularly in relation to health, have been uneven, indicating the difficulties of the practical application of the Constitution. According to Ngwenya (2000), the key issue is not the justiciability of socio-economic rights but their application and enforcement. Ngwenya (2000) argues that access to socio-economic rights has been impeded by a range of factors. For example, challenges to providing minimum essential levels of health have been impeded by poverty related factors such as food shortages, substance, women and child abuse and lack of access to drinkable water which lead to preventable ill health.

1.3. Legislative and Programmatic Reform

Building on the Constitution, and striving to create an enabling process and environment, the state adopted various legislative and programmatic measures which acknowledge and seek to redress the inadequacies and injustices of the past. The new government's ongoing policy development therefore includes a range of social and health related legislation and programmes.

For example. The White Paper for Social Welfare (1997), which is governed by principles of efficiency, transparency and responsiveness, guides state integrated social development approaches, strategies and actions. These principles laid the foundation for partnerships between the state and Civil Society Organisations (CSOs) for provision of relief programmes to deal with the socio-economic marginalisation of people living in poverty (Nefdt, 2003). In line with these principles, a major criterion of poverty-relief programmes is that participants should be mainly women. The acknowledgement that women experience greater depths of poverty than men due to structural inequalities in society, and the moves to create an enabling environment by the state, formed the beginnings of an overarching social services strategy, which effectively created the space for groups of marginalised women, like TWC, to actively attempt to access a range of socio-economic rights.

Furthermore. The White Paper on Transformation of the Health System (1997) forms the basis for the current National Health Act (Act 61, 2003) which seeks

to transform healthcare services and provide for community participation in healthcare decision-making. The Act provides for the South African Patients' Rights Charter (1999) which offers guidelines on patients (and healthcare providers) rights and responsibilities and sets the standards of healthcare patients can expect at healthcare institutions. Additionally, The Batho Pele Principles serve to govern service delivery of the public sector (General Notice 1459. Government Gazette 18340, 1997).

The above measures were created to ensure implementation of the overarching vision of human rights, which include the right to health as enshrined in the Bill of Rights.

1.4. South African Human Rights Commission (SAHRC)

Importantly, Chapter Nine of the South African Constitution (Section 187) requires the creation of institutions to protect human rights, such as the South African Human Rights Commission (SAHRC).⁸ The SAHRC is an autonomous agency charged with promoting and monitoring the protection of human rights and is fully empowered to monitor and investigate the state in regard to the realisation of socio-economic rights. To this end, during 2007 the SAHRC held hearings to inform an investigation into the right of access to healthcare (Government Gazette 29611, 2007), signifying the importance of gathering empirical evidence to inform decision-making in relation to health rights.

During these proceedings, TWC women made a submission to the SAHRC in relation to the difficulties they experience when attempting to access public healthcare services. Their submission included a range of socio-economic factors which impact negatively on their ability to access healthcare; for example, lack of access to public transport services, difficult informal employment conditions and lack of respect and dignity within public healthcare institutions because they are poor. Yet all of these rights are recognised as fundamental to the Constitution.

2. STUDY CONTEXT

TWC is a community-based network of women founded in 2005, two years prior to this research. TWC aims to provide access to information, opportunities and

⁸ www.sahrc.org.za

resources to women from low income communities in Cape Town. TWC calls for development initiatives that include communities and women themselves, as agents of change, who have the freedom and ability to make informed choices. This implies dealing with poverty related factors, lobbying for the strengthening of institutions to deliver services to the poor, ensuring gender equality and encouraging women's empowerment.

A range of issues lie behind the emergence of TWC activities. However, the initial impetus to establish TWC was by four women (including myself), operating in the development sector, who volunteered their time to assist and support community-based projects driven by women. Globalisation has brought opportunities in the form of technology, information and increased cultural diversity within communities, but also diseases, which have created new challenges for vulnerable communities.

People who are poor daily face challenges of food shortages; limited access to shelter, drinkable water; physical violence or ignorance about disease prevention. The vast majority of these people are women. Gender dynamics and power imbalances between men and women in low income households and communities impact negatively on the health of women and girls as outlined further in Chapter 2. Thus, TWC is primarily an example of how vulnerable groups have been forced to defend themselves against the impact of government neo-liberal policies, which have increasingly limited access to resources for the poor.

Initially, in 2005, when TWC was started, it was envisaged to be a rights-based programme which brought women together and assisted in building their capacities to *'speak with one voice'* (See Appendix C: TWC Brochure). However due to a range of reasons, TWC has become more of a skills development programme rather than a vehicle to mobilise women to invoke their human rights.

Currently, TWC consists of groups of approximately ten women, which form community-based Circles with approximately three hundred women associated

with the programme⁹. These community based Circles are normally started voluntarily by women who have initiated or wish to start community-based projects. These women, known as the coordinators of the Circles, gather regularly to share information, knowledge, skills and experiences, collectively generate ideas and seek ways and means of starting or further developing projects which range from income generation activities to home-based care (See Appendix C: TWC Brochure).

Circles are located in the following areas of Cape Town: Bokmakerie, Hazendal, Silvertown, Heideveld, Vrygrond, Retreat, Delft (Leiden, Eindhoven, The Hague, Rosendal, Voorbrug and Suburban), Wesbank, Philippi, New Cross Roads, Old Crossroads and Manenberg. Areas where TWCs were initiated and constituted as individuals, who attend meetings in an ad hoc manner are: Gugulethu, Langa, Khayelitsha, Strand, Ocean View, Nyanga, Atlantis, Strandfontein, Mitchell's Plain and Rugby.

As indicated, these areas where community-based Circles are located are characterised by high rates of unemployment, poverty, substance, women and child abuse, low levels of literacy and high rates of TB and HIV/AIDS which impact negatively on people's development and their health, with the direct result of under-resourced public healthcare institutions being over-utilised and straining to cater to meet the needs of people within these communities.

2.1. TWC's Way of Working

TWC views the promotion of gender equality and empowerment as crucial interventions to improve women's development and health. TWC believes that it is not only necessary to develop gender-responsive policies and programmes, but also that gender gaps must be closed in other areas of development, such as education, access to economic opportunities and ensuring equal

⁹ In describing the 'membership' of TWC the term 'associated' has been used. The notion of membership within TWC is unclear at this stage. It was initially envisaged that women who regularly attend meetings of the community-based Circles and support TWC activities within their communities would be regarded as members and would benefit from the access created by the overarching TWC activities. Currently the coordinators of the various Circles are regarded as the active members of TWC as they facilitate access to opportunities for women in their communities.

participation in society. Secondly, it believes that sustained programmatic interventions are required to enable women to realise their human rights and improve their social status. Thirdly, all development actors, including CSOs, the state and the donor community, must live up to their commitments and deliver services, particularly for the most vulnerable, in our society, which include women.

TWC therefore facilitates relationships between government and development partners to ensure accelerated and coordinated action to meet the socio-economic needs of women as extensions of their families and communities. In the process TWC forges partnerships with a range of actors, who assist and support the women in developing their everyday community-based activities. In addition, TWC acts as a vehicle for locally based women seeking access to information and opportunities, currently out of their reach.

TWC's operational activities are supported by a full-time Coordinator, appointed and employed from within TWC. Her core function is to facilitate relationships with CSOs and the state. In this way TWC acts as a conduit to resources, information and services regarded as socio-economic entitlements in the South African Constitution (Act 108, 1996).

Relationships between TWC, CSOs and the state include the following:

- Epilepsy South Africa for building awareness of human rights of people with disabilities;
- International Labour Research and Information Group (ILRIG) for creating awareness of the impacts of globalisation;
- A range of state departments for creating awareness of human rights during popular campaigns such as Sixteen Days of Activism Against Women and Child Abuse and International and National Women's Days; and
- The University of Cape Town (UCT) for building women's knowledge of the right to health.

TWC became involved with the UCT Health and Human Rights Unit in the School of Public Health and Family Medicine in 2007 through my work as a health researcher and adult educator. I continue to work with TWC on health

rights campaigns through my civil society and University of Cape Town activities. During 2007 I held focus group discussions with TWC on behalf of UCT, in a research project investigating the usefulness of a series of health rights pamphlets and posters. This project resulted in the realisation that these women to a large extent have varying knowledge about their health rights.

2.2. Governance

Within TWC there are rich relationships that have evolved between and amongst the women, crossing many differences and providing the energy that has in part catalyzed the women to build and maintain this community-based network. TWC is managed by the twenty-five coordinators of the community-based Circles. Twice monthly these women meet under the guidance of the TWC overall coordinator as the Coordinators' Forum to strategise and facilitate TWC activities. A Programme Management Unit consisting of three partner organisations – DVV International, Epilepsy Western Cape and Certificate for Youth Trainers (CYT) – support TWC's overarching vision and ensure good governance.

3. RESEARCH MOTIVATION

It should be acknowledged from the outset that I am a founding member of TWC, having worked closely with the organisation since its inception. Throughout my involvement I have seen the women's struggles just to get by on a daily basis and the many obstacles they face when trying to access rights to health for themselves and their families.

In my view, this is because most health rights education activities appear to be based on pamphlets and posters aimed at awareness-raising around the right of access to healthcare. I was immediately interested in the concept of developing education programmes which focus on rights to health, link awareness raising to women's daily struggles and circumstances and help women with information made accessible through facilitated learning and discussion.

Also, after working so closely with the women I often wondered how they perceived my role and if they felt they gained anything from my participation in their activities. In the same way, I was curious about how TWC is viewed in

terms of the role it plays in providing women with access to socio-economic rights. Two years after leaving TWC as the Programme Manager, I embarked on this study.

As someone who has a relationship with TWC since its inception I assume I come with my own views and opinions which may impact on the research, which I outline in more detail in Chapter 3. A key challenge in South Africa is ensuring vulnerable groups such as the women within TWC have access to rights to health. Thus, I assume women would like to learn more about and play a greater role in deciding on issues around their health, thereby being enabled to make informed choices and take control of their lives. As argued by London (2004), a key obligation for the state and part of the state's constitutional commitment to realising human rights is the promotion of the right to health. Thus part of the motivation for this study is to contribute to providing empirical evidence to inform decision-making in relation to advancing rights to health. Any endeavours by the state to meet the objectives of the Millennium Development Goals (MDGs) will have to include advancing the right to health, without which the ambitious MDG targets which aim to improve the lives of vulnerable groups cannot be met.

4. PROBLEM STATEMENT

Despite more than fourteen years of formal democracy, South Africa remains a country with profound inequalities in relation to access and distribution of resources. Evidence to date, London (2003, 2004); Holtman, Ngwenya and London (2004) and Thomas and London (2006) point to the importance of knowing and understanding health rights on the part of communities most vulnerable to the violation of their rights as key to redressing social inequalities.

However, translating awareness or knowledge into understanding, and translating understanding into practice is fraught with difficulties and obstacles, which may explain why, despite having a constitutional framework that promotes the right to health, ordinary South Africans still struggle to realise their health rights. A better understanding of these difficulties and obstacles, and of strategies to overcome these obstacles, particularly in relation to adult learning, may help to identify how best to realise the promise of our Constitution.

This qualitative research study therefore aims to:

1. explore the awareness, understanding and practice of health rights amongst eight women who are part of TWC.
2. investigate whether being aware and understanding that they have rights to health is enough to enable women to overcome factors driving inequalities in relation to their health rights.
3. identify what kinds of strategies are most effective in overcoming obstacles and facilitating access to health rights.

5. PURPOSE OF THE STUDY

The purpose of this study is to provide further insights or identify contradictions in current theoretical debates in relation to rights to health.

Primarily the study's purpose is to identify whether the different theories of adult education can inform the work of the UCT Health and Human Rights Unit, which is currently developing learning programmes around the right to health for a network of CSOs.

Secondly, the study's purpose is to generate knowledge which could assist TWC in understanding the impact it has on women who participate in TWC activities.

Effectively, the purpose would be two-fold:

- a) in the short to medium term to build and strengthen TWC to assist and support the women's capacities to invoke their rights to health, which will enable them to gain increased access to a range of socio-economic benefits, including access to healthcare services.
- b) in the long term to gather empirical evidence which might assist TWC in strengthening partnerships with the state and lobbying government around ensuring rights to health.

This research was conducted in Cape Town between June and November 2007 at a time when TWC made a submission to the SAHRC around the lack of access to healthcare. It was an opportune time to interview some of the women because they were interested in reflecting on their rights to health and access to healthcare services. This study was therefore initiated based on anecdotal

evidence provided by the women during the period when I worked closely with TWC, the SAHRC submission and the workshop around the pamphlets.

This study was not commissioned by TWC and is not intended to be an evaluation of the organisation.

6. AIMS AND OBJECTIVES

Consequently, this study seeks to explore the awareness, understanding and practice of rights to health through interviews with eight members of TWC.

- a) Explore participant experiences which may have influenced their awareness levels, understanding and practice. This includes:
 - identifying the role played by their personal histories and socio-economic backgrounds which include factors such as poverty, unemployment, low levels of education and lack of skills.
 - identifying how, where and what women learn and the impact this learning has on their awareness, understanding and practice.
- b) Explore the successes and challenges they encounter when trying to learn (become aware, understand) or access (practice) their rights to health. This includes:
 - identifying factors which may inhibit or facilitate women's claiming of their health rights.
 - identifying lessons to improve practice.

7. RESEARCH QUESTION

What awareness, understanding and practice of rights to health exists amongst eight women, who are part of TWC?

This links to the following sub-questions:

- a) Is being aware and understanding that they have health rights enough to enable these women to invoke their rights and overcome obstacles in relation to health inequalities?
- b) What kinds of adult learning strategies are most effective in overcoming obstacles and facilitating access to health rights?

8. THEORETICAL FRAMEWORK

This study is inter-disciplinary, spanning a range of domains, and the theoretical framework includes but is not limited to authors such as Nefdt (2003) in the social services; Sen (1990) in the area of development; London (2004); Ngwenya (2000) and Mann, Gruskin, Grodin and Annas (1999) in the health and human rights field.

Furthermore, to analyse the eight women's awareness levels, understanding and practice, this study draws on literature in the field of adult education which includes the Situated Learning theorists (Lave and Wenger, 1991), Phenomenological perspectives (Fenwick, 2001), (Mezirow, 1994) and Radical Feminist pedagogical perspectives of Ismail (2006), Walters (1998) and Weiler (1991) who explore, have links to women's learning and provide theories which have direct relevance to this study in terms of the site of practice (civil society context) and its conceptions of learning and teaching (informal and nonformal). These perspectives enabled me to understand and analyse learning, and argue that learning is contextual with implications for levels of awareness, understanding and practice of rights to health.

9. RESEARCH METHODOLOGY

This study falls within the paradigm of Phenomenology as defined by Maykut and Morehouse (1994) who argue that Phenomenological research begins with the acknowledgement that there is a gap in our understanding which the researcher is required to clarify or illuminate. Phenomenological research therefore does not necessarily provide definitive explanations, but rather increases insight into particular phenomena, which I elaborate upon in Chapter 3.

As indicated, this is not an evaluative study. This study examines a subject which is relatively new in South Africa, i.e. awareness, understanding and practice of health rights within a civil society context. A qualitative exploratory research design was used as advocated by Maykut and Morehouse (1994) and is consistent with Babbie and Mouton (2001). These authors contend that qualitative exploratory designs are valuable when a researcher is examining new phenomena.

The study focused on women for a number of reasons. Firstly, I had easier access to them than men. Secondly, women are regarded as a specific vulnerable group in the Constitution because they suffer persistent inequalities which cause preventable harm to their health due to underlying aspects of their livelihood situations, which are more severe than those of men. The fact that poverty affects more women than men — and it affects women more severely — is well documented within the development literature by Walters (1998), Ismail (2006) and Essof (2005) which I elaborate further in Chapter 2. Thirdly, TWC as my research site focuses on women both as vulnerable individuals and as a group, who have little access to health rights, through no fault of their own but because of societal structures.

The scope of this study is limited to the experiences of eight of TWC's coordinators, who are low income or unemployed women living in townships and informal settlements in Cape Town. Participants mostly understood the right to health as being the right of access to healthcare which impacted on the scope of the study. As explained by these women, public health facilities were perceived as important sites for health rights claims. Thus the study relates to public healthcare facilities and, not to the private healthcare sector.

10. OUTLINE OF THE STUDY

The study is outlined in chapters as follows:

Chapter 1: Introduction and General Background includes as (already outlined) introduction, background, study context, research motivation, problem statement, purpose of study, and aims and objectives of the study.

Chapter 2: Literature Review provides an overview of the theoretical foundation of the study.

Chapter 3: Research Methodology and Design includes an explanation of the research design, population, sampling, ethical considerations and data analysis.

Chapter 4: Research Findings are presented in this chapter.

Chapter 5: Discussion, Conclusions and Recommendations include the analysis and discussion of the findings as laid out in Chapter 4 as well as the conclusions and recommendations of the study.

University of Cape Town

CHAPTER 2: LITERATURE REVIEW

"I just want them to treat me like I'm a human being"
(Ayanda quoted on p 70)

INTRODUCTION

This chapter presents perspectives on human rights and adult education that aim to provide the theoretical foundation of the study.

As indicated in Chapter 1, health rights research is inherently multi-disciplinary and is a newly emerging practice. There is still limited systematic social science research in the field. This study therefore draws on a range of national and international research reports and authors in diverse fields, which include but are not limited to the following domains: Nefdt (2003) in social services; Sen (1990) in development; London (2004), Ngwenya (2000) and Mann et al. (1999) in health and human rights.

The study could not be expediently located within one theoretical school of thought. Therefore the study also draws on a range of perspectives within adult education which include Lave and Wenger (1991); Fenwick (2001); (Mezirow 1994); Ismail (2006); Walters (1998) and Weiler (1991). These perspectives provide a theoretical framework for understanding and analysing the women's learning within a civil society context.

1. CONCEPT CLARIFICATION

As this study is inter-disciplinary and draws on multiple domains, concept clarification is important because it places specific terms in their proper contexts. Some of the key concepts which relate to this study are: human rights, right to health, adult education, informal and non-formal learning, empowerment and agency

Human Rights: The concept, human rights, which informs this study, is based on the United Nations Universal Declaration of Human Rights preamble¹¹. Simply defined, human rights are the basic rights or freedoms which are

¹¹ The UDHR states that *all human beings are born free and equal in dignity and rights* (Article 1. UDHR, 1948). <http://www.un.org/Overview/rights.html>

inherent and to which all human beings are entitled, simply because they are human (UDHR, 1948)¹².

The Right to Health: The 'right to health'¹³ refers to the all encompassing definition of health which enables humans to live a life of dignity and respect as human beings. Therefore the right to health refers to the highest attainable standard of health, the underlying determinants of health and the substantive rights to health. These include the provision of the right of access to healthcare which encompasses access to hospitals and clinics, medical treatment and the necessary conditions for the protection of peoples' health, making the right to health an inherently multi-disciplinary concern.

Adult Learning: Although adult learning is related to many other concepts, for the purposes of this study I draw on Mezirow (1991; 1994) who suggests all learning is based on experience. Learning can be viewed as a process of altering, modifying or transforming an individual's attitudes, beliefs, perceptions and practices with knowledge being created through critical dialogue and reflection, triggering the transformation of experience which then becomes learning (Mezirow, 1994).

As learning refers to the process of learning and how experiences relate to learning *rather than learning outcomes* (Fenwick, 2001:3) I will be foregrounding views which illuminate learning based 'on reflection on concrete experiences' which 'include learning in any form and in any situation' (Fenwick, 2001:1). Additionally, learning is defined as a tool for empowerment and development of the individual as part of the collective in order to take social action (Ismail, 2006).

Informal and Non-Formal Learning: Walters (1998) refers to the ways in which women learn which can generally be described as 'informal' and 'non-formal'. She defines informal learning as 'often unplanned, incidental learning

¹² Human rights norms and standards were developed as a response to the mass executions committed by the Nazis during World War II. This resulted in the United Nations, in 1948 adopting the Universal Declaration of Human Rights (UDHR, 1948). www.unhchr.ch/udhr/lang/eng.htm

¹³ ICESCR, 1966. International Covenant on Economic, Social and Cultural Rights. http://www.unhchr.ch/html/menu3/b/a_cesr.htm

which occurs, for example, while organising community soup kitchens through savings clubs and religious organisations' (Walters, 1998: 436).

Walters (1998) further defines non-formal learning as usually being planned, short-term and non-certified as opposed to formal learning which is long-term, planned and certified by accredited institutions.

Empowerment: The term empowerment is a weighted term, deeply embedded in rhetoric. I have chosen to use this term, based on the adult education definition used by Ismail (2006) which views empowerment as a process through which individuals and groups gain control over issues and problems that concern them most, enabling them to take action and to achieve their objectives.

Agency: The term agency for the purposes of this study is based on Freire's (1967) definition which views agency as an individual's struggle to change the everyday social practices and external structures which shape the world they live and exist in. However, individuals form part of a community and the building and development of individual agency is viewed as being for the greater good of the collective (Freire, 1967).

2. HEALTH AND HUMAN RIGHTS PERSPECTIVES¹⁴

This section outlines perspectives that aim to provide a theoretical framework for the discussion of women's learning in relation to their health rights. Human rights are increasingly being accepted on practical grounds. However, from a theoretical point of view universal human rights are a contested concept with various interpretations.

Cornwall and Gaventa (2005) in the development literature contend that human rights appear to be a particular paradigm gaining increasing credence in international discourse as development actors seek to create space to engage around issues of common concern. Cornwall and Gaventa (2005) maintain that notwithstanding their evident popularity, there is relatively little critical thinking

¹⁴ Human rights principles are enshrined in a range of international, regional and national human rights instruments, which include conventions, declarations and protocols on the international and regional level and constitutions of countries at the national level, some of which are outlined in Chapter 1.

and empirical evidence regarding human rights and their relationship to development processes.

2.1. Human Rights

Pollis and Schwab (1979), in the field of international law, say that one of the key challenges to human rights is the range of interpretations. They argue that some people view human rights as abstract international principles, divorced from people's daily realities. Others view human rights as individual entitlements and an imposition by Western powers for their own political ends which privilege certain groups or individuals in society. These groups often wield this power to protect their privileges with the direct result of effectively limiting vulnerable people's access to socio-economic resources. In direct contradiction, human rights are also viewed as group rights and values prioritising the rights of the vulnerable at the expense of other citizens.

In support of human rights Mann et al. (1999) and An-Na'im (2002) maintain that the above are misconceptions. Human rights are dynamic and develop and change over time as different countries and cultures converge on a common meaning. They argue that though human rights laws are based on Western philosophical traditions, increasingly many non-Western societies have come to identify with the idea that all people are entitled to enjoy fundamental human rights.

In defence of human rights, Shivji (2002) conceptualises them from the position of vulnerable people in Africa and argues that human rights demands are the backbone of democratic struggles and therefore cannot be politically neutral.

2.2. Health and Human Rights

Mann et al. (1999), De Cock, Mbori-Ngacha and Marum (2002) and Braverman and Tarimo (2002), contend that a key weakness in how human rights have been conceptualised is that it has predominantly been preoccupied with individual entitlements and remained largely disconnected from human rights as collective rights.

London (2003; 2004) maintains that human rights instruments articulate the basic minimum legal standards that all societies should meet and should serve

to protect not only individuals but groups as well. Human rights laws can serve to strengthen vulnerable people's agency as rights holders and enable them to negotiate and hold duty bearers accountable for ensuring access to these rights. In this way, vulnerable people are enabled to redress power imbalances without necessarily using adversarial approaches.

Braverman and Tarimo (2002), as cited in London (2003), agree that internationally, there is acceptance of human rights principles but argue that human rights are dynamic and constantly changing. They caution against viewing human rights in an overly simplistic manner as human rights concepts *may mean different things to different people in different societies at different times* (London, 2003:5).

Irrespective of the above theoretical contradictions, important to this study is the understanding that practically human rights laws are meant to protect the vulnerable and the poor, as was initially intended by the UDHR in 1948.

If the guarantee of human rights is a universal goal meant to protect the poor, then vulnerable people, such as the women involved in this study, must be able to access their rights to health to enable them to act to change negative situations in their lives and ensure a better quality of life.

3. WOMEN'S VULNERABILITY IN SOUTH AFRICA

This section provides an overview of vulnerable women's situation and the need for women to know and understand their health rights to enable them to claim access to these rights.

Women, both as individuals and groups, are situated in a vulnerable position in society, through no fault of their own but through traditional societal structures. Internationally, there has been an unparalleled increase in medical technological developments as well as economic resources, during the twentieth century. In spite of these developments, women in South Africa continue to suffer from persistent inequalities which cause preventable harm to their health and force them to lead poor quality lives because of underlying aspects of their livelihood situations.

Economic conditions emerging over the last two decades have exacerbated the problems of vulnerable women in most situations. Decreased expenditure on public healthcare and food subsidies globally¹⁵ mean that increased costs are borne by women, who work longer hours. On average women spend 344 minutes per day on paid and unpaid productive activities combined, compared to 313 minutes for males. Yet women spend more money on basic health-care¹⁶ and face lower wages and fewer job opportunities¹⁷ as indicated below. These factors take a toll on women's bodies that absorb much of the impact of reduced public spending¹⁸. The fact that poverty affects more women than men, and it affects women more severely, is well documented by Walters (1998), Ismail (2006) and Essof (2006) within the development literature, these gendered aspects of global economic processes keep women structurally poor.

Within South Africa, a range of Declarations aimed at eliminating poverty and gender inequalities have been signed, some of which are indicated in Chapter 1. However, women are still discriminated against based on their gender though South Africa has ensured gender issues are addressed in all its policies, programmes, activities and functions since 1994. These amongst others include the fact that women are specifically protected as a vulnerable group in the South African Constitution¹⁹, paving the way for advancing women's rights²⁰ in a range of areas. These include legislative measures such as protection for women around issues of sexual and domestic violence (Domestic Violence Act

¹⁵ <http://hdrsearch.undp.org/>

¹⁶ www.thenation.com/doc/20090831/

¹⁷ South African Labour Force Survey www.info.gov.za

¹⁸ www.statssa.gov.za/.../statsdownload.asp?...womenandmen5yearson

¹⁹ Important for women is that the fundamental purpose of the Constitution is to protect the rights of vulnerable people, and it says that women should not be discriminated against on the basis of gender, race, religion or culture in South Africa (Act 108, Section 27 (1) (c)), protects women's rights in terms of security in and control over their body and access to health care services, (Act 108, Section 28 (1) (c)), protects women's reproductive health care and guarantees the right to have access to emergency medical treatment.

²⁰ Building on the Constitution the new government introduced a range of health and health policy reforms to ensure the provision of safe, effective, affordable and acceptable health care. Within the legislation were the 1994 Reconstruction and Development Programme, which aimed to redress inequities and inequalities of the past, The National Health Plan, which spells out the national priorities for health and the 1997 White paper for the Transformation of the Health system in South Africa. Other important policies include the White Paper on Transforming Public Service Delivery (1997), which puts the public needs first, the Choice on Termination of Pregnancy Act (Act 92 of 1996), which legalised abortion on request. The Patients Rights Charter (1999) seeks to guarantee the realisation of patients rights of access to health care services, thereby ensuring that patients receive quality care (van Rensburg and Pelser, 2004).

No. 116 of 1998) and the adoption of the controversial Choice on Termination of Pregnancy Act (Act 92 of 1996). Institutional structures such as the Gender Commission²¹ and provincial gender desks have been put in place to take on the challenge of implementing plans to advance women's empowerment and achieve equality between men and women.

Some of the gains include an upward trend of women occupying positions of power in South Africa. For example, the number of women parliamentarians has risen from an average of twenty percent to almost thirty percent in the last five years²². However, the above statistics suggest that achievements in gender equality in concrete terms have only benefited those who already have access. Change for vulnerable women has predominantly been at policy level as most institutional structures are inadequately resourced and skilled, and remain relatively weak and unable to implement gender policies and plans adequately. Gender equality therefore has not impacted on the majority of women in South Africa, who continue to live on the margins of society. The challenge to eradicate poverty and ensure gender equality remains critical for South Africa, particularly in relation to health.

3.1. In Relation to Health Rights

Women make up the majority of the population in South Africa, yet poor women still suffer greater burdens of health risks and abuses, despite having a longer lifespan than men²³. In unequal societies, such as South Africa, the

biological advantage of the majority of women is entirely cancelled out by their social disadvantage, offering a sharp reminder that economic development alone will not necessarily allow women greater opportunity to flourish (WHO, 1998).

Men and women face various health problems but reproductive and pregnancy related vulnerabilities, which are preventable, are solely related to women and in South Africa remain amongst the highest in the world (WHO, 1998). Evidence within the field of health indicate that women are more likely to suffer and die from preventable diseases such as TB, HIV/AIDS, pregnancy related

²¹ <http://www.gce.org.za>

²² <http://women3net.org.za/election/wominparl.htm>

²³ <http://www.gega.org.za/download/gomez.doc>

complications and abortions²⁴. According to Statistics South Africa, deaths recorded due to maternal conditions increased from 1997 to 2001, decreased in 2002 and then increased in 2003 and 2004. Statistics South Africa contends that *the death rate from maternal conditions more than doubled between 1997 and 2004*.²⁵ Women's higher morbidity persists even after they are past childbearing ages.

The South African Labour Force Survey (SA LFS), since 2001 when it was first conducted, has consistently recorded a higher unemployment rate among women, than men. The most recent data, recorded in the September 2006 LFS, reports an official unemployment rate of 21,2 percent for men, compared to 30,7 percent among women, due to the lack of recognition of their unpaid 'family' labour.

Bhorat (2007), in an article in The Sunday Times (25 November 2007), suggests the Statistics South Africa and the LFS data are questionable and are not nationally representative in terms of how these studies measure poverty and its estimates of poverty levels. He considers the work done by leading economists van der Berg, Louw and du Toit (2007)²⁶ far more relevant in estimating poverty levels. However, Bhorat (2007) says that irrespective of the contentious debate, what these studies agree on is that there have been no major shifts in household poverty in South Africa since the advent of democracy and the enshrinement of women's rights within the Constitution.

Drawing on the development literature, Essof (2005) maintains that women are the primary caregivers in most families and use their resources to ensure a better quality of life for their children and family. HIV/AIDS have significantly impacted on women in South Africa. Research points to complex links between

²⁴ On 19 September 2006, the Department of Health released the *Saving Mothers – Report on Confidential Enquiries into Maternal Deaths in South Africa for the period of 2002 to 2004* which indicate that during this period 3 406 women died from preventable maternal deaths.

²⁵ Statistics South Africa. 2006. Adult Mortality (Age 15-64) Based on Death Notification and Data in South Africa: 1997-2004

²⁶ Poverty trends since the transition: What we know Servaas van der Berg, Megan Louw, Leon du Toit Department of Economics, Stellenbosch University August 2007
<http://www.sarpn.org.za/documents/d0002783/index.php>

poverty/gender inequality and HIV/AIDS²⁷ indicating that the high incidence of HIV/AIDS means that women take on additional responsibilities as the primary caregivers in the home²⁸ performing unpaid 'family' labour which includes taking care of those too ill to take care of themselves, as well as paying for and administering medication to the ill and dying. Women fulfill this role without getting paid and often without access to clean, running water and sanitation and work in the informal sector, with men having greater access to formal, paid employment.

Sen (1990) says that poverty is not the main reason for women's low health status and quality of life. He argues for the removal of various 'unfreedoms' that women suffer and for the building of women's capacities through education and social reforms. Moser (1993), writing in the field of development, and Mann et al. (1999) from the health rights domain, agree with Sen (1990). They argue that educating women around their health rights results in greater health benefits for their children and families as well as impacting positively on their participation in development activities.

Evidence indicates that social issues and levels of service provision have health impacts. For example, in 2002, Human Science Research Council (HSRC) and the Nelson Mandela Foundation (NMF) conducted South Africa's first HIV/AIDS household survey²⁹. This survey found that people living in informal settlements are most vulnerable to HIV infection. Peoples' living conditions are closely linked to risky behaviour and health issues; where and how women live can therefore tell us a great deal about the health risks they may face.

4. POSSIBILITIES AND CONSTRAINTS

Drawing on perspectives in health and human rights, this section provides an overview of the possibilities and constraints of the Patients Rights Charter and the South African Constitution.

4.1. The Patients Rights Charter

²⁷ South African National HIV Prevalence, Behavioural Risks and Mass Media - Household Survey 2002 new.hst.org.za/pubs/index.php/519/ - 10k

²⁹ South African National HIV Prevalence, Behavioural Risks and Mass Media - Household Survey 2002 new.hst.org.za/pubs/index.php/519/ - 10k

I have used an example outside of the case study to illustrate the contradictory nature of public healthcare institutions. The Cape Argus (19 March 2009) displayed a front page article of the grandmother, who took her grandson, Unabantu to three public healthcare facilities and was turned away. Little Unabantu subsequently died on her back on the way home. In the article the grandmother indicated that: *I still feel that the hospital staff didn't care enough, even though they could see that the child was really sick... Even when I showed the clerks how ill he was, they didn't care. If I had money I would have taken him to Red Cross... maybe he would still be alive today.* Unabantu died due to lack of access to public healthcare service though his grandmother had a referral letter from Red Cross Children's Hospital in her possession.

It cannot be denied that healthcare professionals have more power than vulnerable women attending a public healthcare facility, as they know more about the field of health. Researchers Holtman et al. (2004) reviewed the implementation of the Patients' Rights Charter, and Thomas and London (2006) studying health and human rights within South Africa, showed that women continue to face a range of challenges when trying to access healthcare services. One of the key challenges relates to the historically embedded power relations within public healthcare institutions.

Holtman et al. (2004), in their research study around the Patients' Rights Charter, argue that this is because healthcare practitioners have been viewed as holders of knowledge and play a powerful role in either facilitating or denying access to healthcare. When they interviewed patients about difficulties experienced within the public healthcare context, respondents tended to report issues such as a lack of assistance, aloofness, hostility, lack of communication and the lack of supportive relationships between public healthcare professionals and patients. Holtman et al. (2004) insist that education programmes need to be developed because international and regional treaties, national constitutional provisions and legislative frameworks have little value if the people they were created to protect do not know about them. Within such circumstances, educating vulnerable women to advance their health rights should be of the

utmost importance and it is precisely this relationship which this study wishes to explore.

Importantly, the South African Constitution differs from other constitutions in that it obligates the state to promote health rights as well as provide access to information, providing scope to challenge the state to ensure education and information around health rights which I outline in the next section.

4.2. The South African Constitution

As indicated in Chapter 1, the highest attainable standard of health is an accepted concept within the South African Constitution³⁰. The Constitution further provides for the protection of women as a vulnerable group, the right of access to information and the promotion of health rights, which is particular to the South African Constitution, creating an obligation on the state to educate women around their rights to health.

London (2004) contends that the advancement of the right to health is often constrained by several factors.

Limitations to health rights

As indicated, the Constitution provides for the following:

- Progressive realisation of health rights, means that health has to be attainable within the available resources of the country. Though the state has a responsibility to realise rights to health, it must do so as resources become available, which effectively limits the right to health and narrowly defines it as the right to healthcare.

³⁰ Under the Constitution the following socio-economic determinants of health are protected:

- j) The right to education: Section 29
- k) The right to healthcare: Section 27
- l) The right to food: Section 27(1)(b), 28(11)(c) and 35(2)(e)
- m) The right to land: Section 25
- n) The right to water: Section 27(1)(b)
- o) The right to an environment not harmful to your health: Section 24
- p) The right to social security: Section 27(1)(c) and section 28(1)(c)
- q) The right to basic social services: Section 28(1)(c)
- r) The right to housing: Section 26, 28(1)(c) and 35(2)(e)

³⁰ The Constitution enshrines the state's legal obligations relating to health. Section 27 (2) reads that *"The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights"*

- The ability of people to access health rights is dependent upon whether they are aware of and understand what rights they are entitled to, what having these rights entail and the ability and access to means by which their rights can be ensured.
- Ensuring the right to health requires more than a judicial system. It requires an informed and active citizenry who can lobby and advocate for the, promotion, respect, protection and fulfilment of their rights to health.

However, London (2004) argues that the very factors which constrain health rights also provide scope to advance them.

Scope to advance health rights

The Constitution has created possibilities to advance health rights by providing for the following:

- International human rights laws even though unratified, create the opportunity for vulnerable groups to draw on the ICESCR to ensure implementation not only of access to healthcare but to the highest attainable standard of health.
- The protection of vulnerable groups emphasise that human rights are collective rights rather than individual entitlements.
- Progressive realisation opens the scope for operationalising health rights as evidenced by the Grootboom and TAC case referred to in Chapter 1.
- Rights of access provide information and promotion of human rights, the latter which is particular to the South African Constitution, serving to create an obligation on the state to inform citizens of their right to health, making access to information both a right in itself and an enabling mechanism to realise other rights.

Thus according to London (2004), utilising a human rights framework may be more suited to addressing vulnerable peoples health inequalities than traditional approaches to health and healthcare.

The previous perspectives on health and human rights complement the following discussion which explores the application of adult education methodologies and approaches to women's learning within a civil society

context. These perspectives explore the value of women's learning within informal contexts by concentrating on the development of women's 'voices' and the effect this has in terms of building women's capacities to assert their health rights.

5. WOMEN'S LEARNING WITHIN A CIVIL SOCIETY CONTEXT

This section aims to provide the theoretical framework used to analyse the women's learning as individuals and as a group by drawing on perspectives within the field of adult education.

Given the historical context of post-apartheid South Africa, education, particularly women's education, cannot be seen as neutral (Walters, 1998). Already in 1998 Walters argued that the majority of adult learners in non-formal education programmes were most likely to be female, black, semi-literate and of a low socio-economic standing (Walters, 1998).

A decade later these trends persist. In 2006, the South African Labour Force Survey indicated that 8,6 percent of men had no formal education while for women the figures are as high as 12,6 percent, despite women's commitment to development activities. Thus, women's participation in development activities to improve their livelihoods has important implications for women's learning about their rights to health as a group and as individuals in relation to how and what they learn about their health rights. Women's learning therefore cannot be neutral but has to attempt to bring change to women's situations.

5.1. Learning as a Group: Situated Learning Theorists

This section outlines Lave and Wenger's (1991) views on learning which falls within the Situated Learning theoretical perspective. Lave and Wenger's (1991) views are relevant to this study because they foreground learning in terms of participation within a group which they term 'a Community of Practice'. Learning is not viewed as the primary purpose of the group; learning is embedded in the context and practices of the group, similar to the way learning happens within TWC.

According to Lave and Wenger (1991), learning is regarded as a social practice and happens as a collective, whilst performing activities. Learning is therefore

viewed as a shared process. Women learn through dialogue and activities. Learning happens through observation, participation and experience gained in the group. It is both explicit and tacit and is embedded in the rules of the group, embodied by members and displayed in terms of shared values. Learning is a means to enhance the value of activities of the group; knowledge and skills acquired are seen as context dependent and not easily transferable.

The concept of Community of Practice and its related concepts therefore have important implications for how and what information women access in relation to their health rights as they predominantly rely on members of the group for information to support their learning. If the context does not allow for new learning to happen, then current practices may not change. This may be an important factor for TWC to consider in future.

Ismail (2006), in her study of women and their housing rights, which is a key socio-economic determinant of health, says that for individual women, learning is about contributing to the Community of Practice, while for the group, the creation of new knowledge within the Community of Practice is aimed at maintaining current ways of performing activities.

This study draws attention to the fact that we cannot focus only on knowledge (new information and ways of acting in the world) as the key to changing practices. This study therefore calls for acknowledgement and a greater understanding of how women learn within informal contexts.

5.2. Learning as Individuals: Perspective Transformation

For the purposes of this study, Mezirow's (1991; 1994) views on transformative learning provide a theoretical basis for how women learn as individuals.

In Mezirow's (1991; 1994) view, the way an individual sees the world is central to the learning process, with learning being a personal experience, which entails development of the individual. However, women, as adult learners, are caught up in their own histories and make sense of their experiences by starting with what they know. They operate within the confines set by their current ways of viewing and understanding the world, which they have acquired through prior learning and experience, which is the foundation for any new learning.

Mezirow (1991; 1994) also argues that it is a basic human need to try to understand and make meaning of our experiences. But individuals are all trapped by the ways in which they 'see' the world. Only once individuals are aware of these 'filters' can they then identify why something is viewed in a particular way, and then be able to understand these experiences better, and perhaps then incorporate unknown aspects of how 'the world is' and find 'new' ways to act in it (Mezirow, 1994).

Mezirow (1994) further argues that learning for any individual is dependent on key interacting elements within the learning context. The individual's way of viewing the world within which learning is embedded informs how the learner constructs meaning. He stresses the need to create a social context which will enhance learning where the individual and his or her assumptions about experiences can be recognized, acknowledged and shared with others. This does not mean that the individual's assumptions are confirmed, but the individual as a person is validated whilst critically engaging with problematic assumptions. Taking the self-image of the learner into consideration is important, as the learning context is concerned with how the learner feels and views it, impacting on how individuals interpret and reflect upon their interpretations. The context within which learning happens is also remembered by the learner in his or her interpretation of what is learnt as it is impossible to separate elements of a social situation.

This view is consistent with Knowles (1970) cited in Fenwick (2001) who emphasizes that adult learners have a range of different life experiences, which they draw on in the learning situation. This suggests that the context in which the experience takes place may determine the extent to which previous learning is used, particularly within public healthcare institutions, where healthcare professionals are usually in charge and have traditionally made important decisions in relation to women's health. These traditional healthcare practices may be discordant with particular behaviours which could reduce women's power to assert their health rights. How then can women be expected to display agency, speak out and claim their health rights within such a context with all its historical embedded power relations? London (2004) argues that human rights

frameworks provide room to negotiate these terrains without being adversarial, enabling women to hold duty bearers accountable and to access their health rights.

5.3. Impact of Power Relations on Women's Learning: The Radical Feminists

This section provides perspectives which explore embedded power relations within the contexts in which women's learning in relation to their health rights practices is meant to occur. Furthermore these perspectives provide views on learning which aim to mobilise women to take action in relation to their health rights.

Freire's (1967) emancipatory views on education as a tool for empowerment have had a profound influence on feminist pedagogies, which fall within the Radical Critical tradition of adult education. Freire's (1967) views on 'critical self-reflection', the development of 'voice' and 'agency' are a central element of feminist pedagogies, as they recognize that individuals form part of a community where learning happens as a group. Freire (1967) emphasises the building of social agency as being for the greater good of the collective, enabling individuals to examine external structures that determine and shape their perceptions of the world.

For this very reason, within the Feminist literature, Ismail (2006), Young-Jahengeer (2003), Walters (1998) and Weiler (1991) criticize traditions that foreground the development of the group or the individual in the absence of the influence of issues of power and power relations within the learning context. They argue that these perspectives' neglect of the broader, historical and structural relations of power at a societal level may be replicated within the dynamics of any 'Community of Practice' (Ismail, 2006). Feminist critics of these perspectives argue that these power-neutral approaches fail to ensure that learning mobilises women around an agenda for social action, which is at the heart of Radical Feminist pedagogies.

Feminist writers Young-Jahengeer (2003) and Walters (1998; 2000) draw on the Critical Radical tradition, especially Freire (1967), and emphasise the

engagement of power relations, the inequities and inequalities in a patriarchal society, which hamper and limit women's development and impact on how they view the world. They argue that understanding how women respond to issues such as race, gender, class and other structures in society, which can be replicated within the learning context, has important implications for how and what women learn.

Walters (1998) suggests that knowledge gained could serve to reinforce power structures and gender hierarchies and that learning may not necessarily translate into knowledge or action. She argues that women's viewpoints are relative to where they are located in any social structure. Learning as part of social processes can either reinforce the embedded 'gendered power relations' (Walters, 1998:437) or challenge them. Therefore, education within informal contexts within a patriarchal society should be positioned to support the struggles of women in oppressed communities, both as groups and individuals, enabling them to embark upon social action to bring about change.

Challenging embedded power relations within their contexts is critical as women's inability to access their health rights does not happen in a vacuum. In order to build women's agency, it is essential to understand women's contexts or it will be impossible to introduce the fundamental changes needed to access health rights within patriarchal societies.

As indicated previously, there is a need to understand how women live and exist in a patriarchal society and how this relates to their learning in relation to health rights. This understanding will enable the development of appropriate human rights education programmes, which create knowledge, speak to issues of power and enable women to claim their rights.

5.4. Reciprocal Relationship between Individual and Group Learning

Feminist writers Belenky, Clinchy, Goldberger and Tarule (1986), cited in Ismail (2006), focus on working class women within a public healthcare context and suggest that there is a reciprocal relationship between individual and community learning. In their study Belenky et al. (1986) describe how women who come from disadvantaged backgrounds and seek medical advice in a health clinic

learn by listening and receiving knowledge. They claim that in their study, women had low self-image and little confidence, which impacted on their ability to raise issues and speak out, using what the authors term 'voice'. These women assumed that health professionals were the authorities who held the answers to their health questions.

Thus for Feminists, the term 'voice' is seen as referring to women's intellectual development. Belenky et al. (1986) maintain that typically women are raised to believe that taking care of others is central to their life's work. Poor women help others by listening, understanding or teaching what they know. Through engagement they come to hear, value and strengthen their own 'voices' as their confidence is built. In the view of Belenky et al (1986) when women use the term 'voice', they are building their confidence, developing their critical thinking and becoming more self-directed.

This view is consistent with the views expressed by Hayes and Flannery (2000) in that the term voice is associated with the exchanging of ideas and the means of connecting with others. Through engagement with others, individuals collaboratively construct knowledge and through this process develop a sense of identity.

In support of Belenky et al (1986), Luttrell (1988), quoted in Ismail (2006), in her study of working class women, defines how women distinguish between what they term 'common sense' knowledge (knowledge gained through experience) and 'school-wise intelligence' (knowledge gained from books or experts). In all three studies women shared similar ideas about caring for others and drew on common sense knowledge as an important way of judging and evaluating what people said they had seen or experienced. Luttrell (1998) argues that despite lacking scientific knowledge, by relying on friends and neighbours who have had similar experiences, women's common sense knowledge enables them to find working class solutions to their problems. Women seek advice from trusted people, not because they are experts but because they share similar challenges and experiences. Luttrell (1988) says that women refer to their common sense knowledge as intuition and feelings. She suggests that for these women,

knowledge which is developed in the collective and in the practiced is often more secure than expert knowledge.

Consistent with this view, Gilligan (1993) says that women develop a sense of confidence; when they can speak freely and hear their own voices clearly, they then begin to build this sense of confidence within themselves. Walters (1998) agrees that for women, finding their voices and articulating their feelings is an important, first step in confronting the challenges in their daily lives.

Important for this study is Gilligan's (1993) argument that women must not only find their voices but must build a critical understanding of women's rights, to ensure development and change. If not, their learning will not translate into action, which is at the heart of radical discourse (Ismail, 2006) and one of the key issues this study wishes to explore.

CONCLUSION

In conclusion, this theoretical framework has enabled this study to argue that educating women in relation to their health rights should aim to support women's agency as individuals and a group (as a first step leading to advocacy and civil society mobilisation) which is more suited to addressing health inequalities than traditional (bio-medical) approaches to healthcare.

Drawing on London (2004) within the domain of health and human rights, health rights education programmes should:

- be directed at redressing injustices rather than easing people's suffering;
- build women's agency as individuals for collective action rather than individuals as collective efforts are needed to drive change;
- take into consideration the context within which health rights learning happen to enable the building of individual and collective agency to drive change;
- assist in identifying rights-holders and duty-bearers and enhance the accountability of the state;
- acknowledge the importance of power as key dimensions of women's learning in relation to health rights ensuring that the discourse moves from

needs to rights and violation of the rights of the most vulnerable in our society; and

- enable women to develop a voice and embark upon social action as the starting point to assist in accessing rights to health.

In order to understand and analyse women's learning, particularly as it relates to their health rights, it is critical to take into consideration the contexts within which their learning is located and embedded.

Adult learning provides theories, which enable us to understand elements and processes of learning, development and change in the human rights domain, particularly as they relate to women's learning within informal contexts. This enabled the study to:

- examine the women's different processes of learning and the role the Women's Circle plays in supporting women's learning;
- explore women's learning around their health rights as individuals and as a collective within informal contexts; and
- provide insights into the women's learning by exploring the context within which women learn.

In the following chapter I discuss the research methodology which includes an explanation of the research design, population, sampling, ethical considerations and the data analysis process.

CHAPTER 3: RESEARCH STRATEGY AND METHODS

"You know there is something wrong but you are too scared to say something because you are scared the nurses are going to chase you away..."

(Helen quoted on p 72)

This chapter provides an overview of the research strategy and methods, outlining procedures, processes and analyses used to answer the research question.

1. RESEARCH DESIGN

As indicated in Chapter 1, this is a qualitative research study which falls within the paradigm of Phenomenology as defined by Maykut and Morehouse (1994), who view Phenomenology as an interpretive paradigm. Phenomenological research begins with the acknowledgement that there is a gap in our understanding which the researcher would like to clarify or illuminate. Phenomenological research does not necessarily provide definitive explanations but increases insight into particular phenomena. This philosophy or method of inquiry is based on the premise that reality consists of events as they are perceived or understood by participants and cannot be independent of that perception. Thus, this method is highly appropriate for this study because the role of the researcher is to work with participants, as members of a community, to help turn tacit, unarticulated problems into explicit identifiable topics of collective investigation and understanding. The role of the researcher is to interpret the findings from participants' awareness, understanding and practices of human and health rights.

I used an exploratory research design because the aim was to research a subject that is relatively new, i.e. women's awareness, understanding and practice of their health rights within a civil society context. This is consistent with Babbie and Mouton (2001) who argue that exploratory designs are valuable when a researcher is examining new phenomena. An exploratory design assisted me to illuminate factors which inhibit or facilitate vulnerable women's awareness, understanding and practice of their health rights within a civil society context, about which little is known. This design simultaneously enabled

me to describe the situations of the women so as to understand them better. Furthermore, it enabled me to contribute to work currently developing in the field of human rights, as there does not seem to be much literature using qualitative research methods for health as a human right.

1.1. Research Method

This is a qualitative research study and not an evaluation of TWC. Denzin and Lincoln (1998, 3) offer a generic definition of qualitative research:

Qualitative research is multi-method in focus, involving an interpretative, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of meanings people bring to them.

A qualitative research method is therefore highly appropriate as the aim of this qualitative study is to examine human behaviour and the social world people live in. It is extremely difficult to define human behaviour in simple, measurable terms. Measurements tell us how often or how many people behave in a certain way but they do not adequately explain why people behave the way they do. Research which attempts to increase our understanding of why things are the way they are and why people act the way they do is “qualitative” research (Maykut and Morehouse, 1994). This study aims to explore women's awareness, understanding and practices of their rights to health. Implicit in this is “how” and “why” women become aware and understand their health rights and “how” and “why” they act in particular ways, which is the aim of qualitative research.

2. SCOPE OF THE STUDY

Spivak (1988), a researcher within the Feminist tradition, argues that women are not a homogenous group but diverse, and factors impacting on low income women are not necessarily the same as factors impacting on middle-income women. And factors impacting on one woman would not necessarily be experienced in the same way by another. This study was concerned with exploring and illuminating the awareness, understanding and practice of human rights, particularly the right to health of poor women who are part of TWC. Thus the scope of this study is limited to the experiences of eight of TWC's

coordinators, who live in townships and informal settlements in Cape Town. The study uses quotes to give voice to these women as individuals and as a group.

As indicated in Chapter 1, the participants mostly understood the right to health as the right of access to healthcare, which impacted on the scope of the study. As explained by these women, public healthcare facilities were perceived as important sites for health rights claims. Thus, as previously stated, the study relates to public healthcare facilities and not to the private healthcare sector.

The study therefore provides a description of women's experiences within their communities. Furthermore it provides insights into their experiences and their learning within TWC and public healthcare contexts, because sites of learning as explained by the women are relevant to this study. This study does not seek to provide descriptions of the impact of their experiences on their families and their personal health issues. Finally, the study is not an evaluation of TWC, nor does it view the right to health as being limited to the right of access to healthcare only.

3. SAMPLING AND SELECTION OF PARTICIPANTS

My sample selection followed the guidelines on purposive sampling as outlined by Miles and Huberman (1994). Purposive sampling is done for both conceptual and theoretical reasons, not to represent a bigger population. It is a deliberate process of choosing respondents based on their ability to provide much needed information on particular phenomena and not to generalise information to a broader population. This implies that the researcher may designate a particular site, which is appropriate for the study and choose respondents who are readily accessible rather than a random sample. My sample was drawn from the coordinators within TWC as they are integrally involved in the programme and I felt that they would be able to provide diverse perspectives concerning awareness, understanding and practice because they come from different communities.

An initial meeting was held where the study was introduced and the interview format and criteria were clarified. Following the presentation, the women agreed to provide the coordinator with a list of volunteers. On receipt of the list, the

coordinator assisted in identifying possible participants. Her knowledge of the volunteers enabled the identification of women. The selected participants were from different age groups, marital status and communities allowing exposure to a range of learning contexts. I hoped that their variety of life experiences would add value to the study.

A concern was that the coordinator would know who was on the list which could compromise anonymity. Also, she could have chosen women who were capable of answering the questions in the "right" way, so as not to reflect badly on the programme. I dealt with this by having more respondents than needed and then chose against my criteria as indicated above. These issues could be considered a constraint and could possibly be a factor which influenced the findings of the study. However, the coordinator facilitated easy access to participants which would not have otherwise been possible.

4. DATA COLLECTION

Given that this is explorative qualitative study I decided to collect data through in-depth interviews with each of the participants. In preparation I compiled guiding research questions to assist me in conducting the interviews. In order to fine-tune my guiding questions I conducted a pilot interview. Much unrelated information was given by the participant to some of the questions I posed, causing me to amend some of the questions as included in the attached interview guide (See Appendix A).

As displayed in the interview guide I used a number of open-ended questions followed by probing questions. This allowed respondents to respond freely in their own words, describe their views, and initiate and sustain a type of dialogue with me. The approach also enabled me to obtain first-hand information allowing me to develop theory and content from the women's stories, their needs and the resources they are using in their lives, as suggested by Maykut and Morehouse (1994). All interviews lasted between forty five to sixty minutes and took place at a time and location preferred by respondents. I ensured that discussions were tape recorded as advocated by Yin (1994) and carefully transcribed for later use in data analysis.

5. DATA ANALYSIS

Within Phenomenology, which is an interpretive paradigm, data collection and data analysis are done simultaneously as advocated by Maykut and Morehouse (1994) and consistent with Cresswell (1997). Similarly in this study, all data from the interviews were transcribed and analysed together with my field notes. I commenced the data analysis process at the end of the first interview and continued in this vein throughout the data collection process. Qualitative data analysis occurs concurrently with data collection rather than sequentially. An evaluation of the rigor of a qualitative study is based in part on the logic of the emerging theory and the clarity with which qualitative analysis sheds light on the studied phenomenon. These are presented as contextual findings, reflecting the purpose of the research (Yin, 1994).

Thematic content analysis was used to interpret the data as advocated by Maykut and Morehouse (1994). This is a procedure for the categorisation of information to enable the researcher to classify or summarise data. The content analysis was done on two levels. Firstly, to provide a descriptive account of the data, i.e. this is what respondents actually said. Secondly, since this is an interpretive study, analysis was also concerned with what was meant, or what was inferred or implied by what respondents said.

The data was initially transcribed verbatim. Firstly I took a copy of the transcript and read through each of the transcripts a number of times to become familiar with the content, looking for patterns in the data. The procedure involved a series of steps. When I saw something that contained interesting or relevant information, I made a brief note in the margin about the nature of the information and colour coded each transcript according to initial broad categories which emerged from the women's stories.

Then using my guiding questions as a framework to provide initial categories and conceptual names, the data were then matched to categories accordingly. This enabled me to continually develop and refine my categories resulting in the formulation of more detailed categories and sub-categories. Thus the findings presented in Chapter 4 are a thematic series of reviews and reflections of participant responses, changing levels of awareness and value statements,

which according to Maykut and Morehouse (1994), is the essential task of the researcher, i.e. to try and get to the heart of the matter by looking for themes that are hidden in the unexamined events of everyday life and finding meaningful, shared themes in different peoples descriptions of common experiences. This helped me to provide rich portraits of practice as held by McMillan and Schumacher (1993) whilst simultaneously illustrating themes emerging from the data and facilitating and enabling the voices of the women to come through (Spivak, 1988).

Drawing on multiple perspectives within the domains of health, human rights and adult education, data and relevant theoretical perspectives were constantly compared with the women's individual narratives and use of language informing the content of the research as advocated by Yin (1994).

5.1. Validity and Reliability

I acknowledge that the women's voices have been filtered through my interpretation of them as the researcher and through their own interpretation of reality and how they chose to construct meaning during the interview process.

The role of the researcher is incredibly important in qualitative research, which is interpretative, and therefore the biases, values and judgements of the researcher have to be clearly stated. My role is not only acting as the primary instrument for data collection but also engaging with the outcomes as well as with the whole research process (Creswell, 1997). Though I occupy various roles, in relation to this study, I did not see any separation in my roles, as the values that guide me as an adult educator, researcher and one who has close ties to TWC are identical.

Oakley (1981) argues that Feminist interviewers have to develop relationships and validate women's subjective experiences (as women and as people). The information elicited from the interviews depends on the ability of the interviewer to establish rapport and gain the trust of the participants, developing these relationships over time as researchers gain participants' trust (Oakley, 1981).

In my view a relationship already existed between me and members of TWC, built over time and based on mutual validation and trust. I firmly believe that the

women view me as a person of integrity, who will not abuse their trust. This made 'conversation' easier during the interviewing process and enabled me to generate rich data for the study which could have been more difficult for an outsider.

However, as recommended by Guba and Lincoln (1981), research is regarded as credible when representing accurate descriptions or interpretations of the target audience's experiences. Thus I ensured that copies of the transcripts were provided to respondents for comment before inclusion in the report. A copy of the report was handed to respondents and TWCs management team before submission for assessment purposes. However, I clarified that the report is my understanding and view of the process.

I have also continuously held discussions with my supervisors which contributed to and deepened my reflexive analysis. As suggested by Guba and Lincoln (1981) and Yin (1994), I further ensured that there were no unexplained inconsistencies between the data and its interpretation. Credibility of my research will be increased when interpretations can explain any contradictions that may arise.

Finally, to increase reliability of the study the following measures were taken:

- All assumptions and presuppositions were explained at the beginning of the study.
- Instances where data collection may have been compromised and could affect findings have been noted.
- Due care has been taken so that inferences drawn from this study are consistent with the data collected by building up a clear and unambiguous "audit trail" as advised by Guba & Lincoln (1989:81). This is achieved by providing copies of the consent forms, guiding questions, excerpts from the original interview transcripts and copies of organisational documents which were utilised in accordance with the constant comparative method of data analysis as set out by Maykut and Morehouse (1994).

Around the issue of internal validity, I draw on Richardson (1994) who concludes that comprehensive research may be a more realistic goal for

qualitative research than internal validity. Therefore I have, for example, shown the range of women's responses, which allow for comparisons to be made, which according to Richardson (1994) is more helpful than triangulation. This approach conceives of complementary rather than competing perspectives; she offers the term "crystallization" as an alternative to triangulation.

Additionally, once I had completed the data analysis process and identified the categories and subcategories, I conducted "member checks" as advocated by Merriam (1998). These were undertaken by consulting the coordinator and the TWC programme management unit on the credibility and plausibility of the findings, and by asking a colleague to comment on the findings as they emerged. I have tried to provide a contextual background to the research, making it possible for others to understand the context and therefore experience it.

5.2. Ethical Considerations

I share Neuman's (2000) view that ethics begins and ends with myself as the researcher and that my personal moral code has to be my strongest defence against unethical behaviour. However, ethical consent for the study was obtained from The Women's Circle Programme Management Unit, the women involved in the study (See Appendix B: Consent Form) and from the University of Cape Town Research Ethics Committee. I further ensured that respondents remain anonymous, using pseudonyms in the transcription, analysis and discussion of the findings. All data gathered was treated with the utmost confidentiality. No information was publicly released in a way that links individuals to specific responses and under no circumstances was the research data discussed in the context of The Women's Circle.

5.3. Methodological Challenges

While the research strategy is theoretically defensible and the insights gained from the in-depth interviews are valuable, some logistical challenges arose. Unfortunately I was unable to provide translations for the Xhosa speaking women as I had initially intended; interviews were done in English and Afrikaans only as I speak both languages fluently. Secondly, some of the women I wished

to include in the study were not available during the period of my fieldwork. However, none of these challenges were insurmountable.

CONCLUSION

In this chapter I presented the research design and the research method of the study. The sampling procedure, data collection process and data analysis were outlined which assisted me in answering the research question of this study. The research methods used served to fairly and accurately describe the critical aspects of the study so that other researchers can test the transferability of the research embarked upon in this study.

The next chapter presents the research findings.

University of Cape Town

CHAPTER 4: PRESENTATION OF THE FINDINGS

"There is so much shame that goes with free"

(Gugu quoted on p 70)

INTRODUCTION

This chapter presents the findings of the empirical study for the data gathered using thematic analysis.

Key themes emerging from the data are the following:

1. Participant profiles, life experiences and socio-economic contexts.
2. Levels of awareness, understanding and practice of health rights.

The themes are divided into sub-themes based on interview analysis.

Sub-themes emerging from the data are the following:

- 2.1. How women learn about their rights
 - 2.2. How women feel about their rights
 - 2.3. Women's interpretations of human rights generally
 - 2.4. Women's interpretations of their rights to health
 - 2.5. Women's views on the state's role in promoting health rights
3. Factors within TWC which enable awareness, understanding and practice of health rights.
 4. Barriers to awareness, understanding and practice of health rights in relation to TWC and within public healthcare contexts.

The study uses participants' quotes from the interview transcripts for the following purposes:

1. To illustrate themes emerging from the data and show the breadth of participant responses as they relate to a particular theme.
2. To help provide evidence for analysis and interpretation in order to strengthen the credibility of the overall findings.

3. To facilitate and enable the voices of the women and to let the voices of the women come through in the findings.

The study acknowledges that the women's voices have been filtered through my interpretation of them as the researcher and through their own interpretation of reality and how they chose to construct meaning during the interview process.

1. PARTICIPANTS' PROFILES, LIFE EXPERIENCES AND SOCIO-ECONOMIC CONTEXT

This section provides an explanation of who these women are, which includes participants' profiles, life experiences, a brief history and socio-economic contexts.

1.1. Participants' Profiles

The following presentation provides explanations of women included in the sample both as individuals and as a group³¹.

Eight women participated in the study, including the TWC coordinator, four Black and four Coloured³² women from lower income communities on the Cape Flats, who are all members of TWC.

³¹ The names of people and places used in the profile and life experiences are pseudonyms. This was done to maintain anonymity (Patton, 1990:356).

³² Acknowledging that the terms Black and Coloured are problematic and that there are different understanding of the terms, for the purposes of this thesis, the terms Black refers to black South Africans who are descended from isiXhosa cultures and Coloured refers to people who are of mixed origin and speak English or Afrikaans (Ismail, 2006).

Table 2: Participants' Profiles

Participant	Ayanda	Bulelwa	Caroline	Dorah	Elaine	Farhaana	Gugu	Helen
Age	58	35	37	34	70	33	44	57
First language	Xhosa	Xhosa	Afrikaans	Afrikaans	Xhosa	Afrikaans	English	Xhosa
Race	Black	Black	Coloured	Coloured	Black	Coloured	Coloured	Black
Born	Eastern Cape	Gugulethu	Heideveld	Heideveld	Eastern Cape	Parkwood	Woodstock	Somerset West
Learning ³³ background	Completed primary school	Completed high school	Did not complete high school	Completed high school	Did not complete primary school	Did not complete high school	Completed high school	Did not complete high school
Number of children	6	1	3	1	5	3	3	5
Marital Status	Single	Married	Widow	Married	Widow	Married	Married	Married
Involved in health programmes	Yes	No	Yes	No	No	No	Yes	Yes
Employment status	Community Worker	Domestic worker	Community worker	Admin	Pensioner	Trainer	Coordinator	Home-based care worker
Shelter	Shack	House	Backyard Shack	House	Shack	House	House	Shack
Politically active during apartheid	No	No	No	No	No	No	No	No

Table 1 indicates that the eight women's ages range from between thirty three and seventy years. None of them were born in the communities they currently live in. For the majority of the women English is not their first language. Literacy levels of five of the women are generally at a functional literacy level, i.e. able to read and write, with the exception of the Coordinator and two of the other women, one who assists TWC with administrative tasks and the other with domestic tasks. These women are married, single, divorced and widowed. They are all mothers and the ages of their children range from six to mid thirties. Some of them are grandmothers and great grandmothers. Four of the women (three Black and one Coloured woman) live in informal dwellings and others live in brick and mortar houses.

Some of the women are directly involved with health programmes in their communities and also involved with the People's Health Movement³⁴. The

³³ I gained the impression the women were not comfortable indicating which level of education they completed, particularly those who have functional literacy, primary school education. Therefore I kept the question relating to education general.

majority of the women are not employed on a full time basis and act as voluntary workers or part-time staff. Only the coordinator is a full time employee of TWC. None of the women were involved in political activities during the Apartheid era³⁵.

1.2. Participants' Life Experiences

Below I present a brief history of the participants because reflecting on personal experience is part of the methodology used in this study and identifies these women.

Ayanda is fifty-eight years old, was born in the Eastern Cape and has functional level literacy skills. She is single, has six children, four boys and two girls, is a grandmother and acts as a voluntary community worker. There is a high unemployment rate in her community and she teaches unemployed women sewing and beading to help them generate an income. In the last four years she has trained approximately three hundred and forty women. While teaching them beading and sewing skills she encourages the women to learn to speak English since the women in her groups speak predominantly Xhosa. A large part of her community is an informal settlement and people live in overcrowded conditions with no sanitation and running water. There is a high rate of Tuberculosis (TB) in the community. Ayanda, as part of a group of community women, provides home-based care services for TB sufferers. Weekly she and the group also cook and feed approximately four hundred and twenty children from the local primary school.

³⁴ The People's Health Movement (PHM) is made up of health networks and activists who have been concerned by the growing inequities in health over the last 25 years. The PHM calls for a revitalisation of the principles of the Alma-Ata Declaration which promised Health for All by the year 2000 and complete revision of international and domestic policy that has been shown to impact negatively on health status and systems. (<http://www.phmovement.org/en/about?PHPSESSID=49f7c8c8cc2541ece734f6ba4e008e91>)

³⁵ Deborah Gaitskell (1983) an anthropologist, initiated research on black women in South Africa during this period. Like in this study, she paid attention to women's roles and life experiences as they relate to their political and economic subordination. Gaitskell (1983), quoted in Kalpana (2005:1), argues that:

in trying to support themselves and their children, black women lack access to any meaningful political power, while the government pursues a policy of systematic dispossession and forced population removals which bears most harshly on women, children and the old.

Bulelwa is thirty five years old, recently married and has one daughter, aged twenty. Her first language is Xhosa. She grew up in a township in Cape Town which she considers extremely dangerous. She feels very differently about the township she is currently living in because there is a constant presence of police and private security companies. Bulelwa completed high school and wanted to study nursing. Despite being accepted at university, she was unable to pursue her studies due to unavailability of financial assistance. Currently, she is employed by TWC as a domestic worker to generate income. However, she still wishes to pursue her dream of becoming a nurse. Bulelwa is not actively involved in any community activities, outside of her participation in TWC activities.

Caroline is thirty-seven years old, the only sister in a family of four siblings and has functional level literacy skills. Caroline finished grade nine and is currently a voluntary community worker. She is a widow and lives with her three daughters in a township she describes as *"having lots of gatekeepers"*, which impacts negatively on community members' access to and use of community buildings and resources. Her community has one of the highest HIV Aids and TB prevalence rates on the Cape Flats. Drugs and alcohol abuse in her community is a key concern for Caroline as she sees a link between the high HIV infection rate, drug abuse, prostitution and the school drop out rate where she lives. Most of Caroline's time is spent assisting community members around health, housing, drug related issues and women abuse.

Dorah is a thirty-four year old, married woman with one child. She completed high school and went to work for a company providing non-accredited soft skills training. While employed, she went on an uncertified secretarial course and now assists the coordinator with administrative tasks. She says that within her community, people support one another in their daily struggles. But she also goes on to say that there have been incidents around child abuse in the community, where the community turned a blind eye. There is a high alcohol and drug abuse rate within her community and recently her brother was killed by a hit and run driver when coming from a bar in the area. Sadly to date the driver has not been apprehended.

Elaine is a seventy year old pensioner, with five children and a number of grandchildren. She speaks Xhosa and some English. She has been living in one of the oldest informal settlements in Cape Town since 1991. She is originally from the Eastern Cape and struggles to read and write as she did not finish primary school. She claims the community she grew up in did not consider educating girl children important. Being able to read and write was viewed as more important for boys. Elaine receives a pension which she says is not enough to live on. To try and generate extra money she is learning sewing, beading and painting through TWC. Within her community she assists voluntarily with soup kitchens and a community garden project. She claims that people within the community do not understand that they have to voluntarily start and participate in projects if they want their projects to succeed.

Farhaana is a thirty-three year old devout Muslim, married with three daughters. She has functional literacy skills and did not complete high school. She is one of eight siblings. She grew up in a protected environment and was not allowed to play with other children in the community. At a young age, she moved to the township where she is currently living. After twenty seven years in the area, she still feels that she doesn't know much about her neighbours and people within the community. She has done a series of art and craft courses and was approached by one of the TWC coordinators to share her skills with the TWC women to assist them in generating an income. For Farhaana, TWC has provided her with the space to build her confidence and meet other women.

Gugu is forty-four years old, married with three sons. She completed high school at a reformatory and then did a basic secretarial course. Gugu was fostered by a woman from the community, where she currently lives. When her foster mother died she inherited the house, where she and her family now reside. Over the years, she has held down a range of jobs as a cleaner moving on to become a supervisor in a clothing factory. She then got an opportunity to work in a restaurant as a chef where she worked for five years without being paid a professional's money as she did not have the requisite accredited skills. She has been on a range of adult education courses since joining TWC. These

include facilitation, project management, report writing and a computer course. She now acts as the TWC coordinator.

Helen is fifty-seven years old and her youngest child is eighteen and still at school. She has three grandchildren and one great grandchild. Her nine year old grandson lives with her. She is not from Cape Town and moved to an informal settlement on the outskirts of Cape Town first before moving to the community where she now lives. She is involved in home based care in the community where she predominantly cares for people with HIV Aids or TB. Helen is currently on an accredited home-based care programme arranged by TWC. She also cooks for orphans of people who have died of Aids. She is concerned about the crime levels within her community, which she feels has been escalating over time.

1.3. Analysing the Profiles

Respondents' profiles and life experiences indicate that these women are not a homogenous group or undifferentiated category. Differences and similarities exist among these women who are diverse in age, 'race', levels of poverty and life experiences.

a) Similarities in participants' socio-economic contexts

In their socio-economic context, the women's narratives indicate that they experience a pattern of marginalisation and discrimination. Their daily lived realities are shaped by multiple vulnerabilities. These include lack of income, education, 'marketable' skills and employment. The social impacts of high levels of crime, alcohol, drug abuse, sickness and disease are related to lack of access to clean water, sanitation and comfortable, satisfactory housing and living arrangements. Health rights as enshrined in international documents and in the National Constitution as an obligation of the state, appear to have little bearing on these women's daily lived realities.

The findings indicate a range of constraints which exist and impact on the women's health rights. These include key elements of women's lack of control and autonomy over their health and lives, lack of access to socio-economic resources and opportunities, as well as the gendered division of labour. Yet, as

indicated in Chapter 2, a considerable body of new legislation has been passed since 1994. The particular focus of some of this legislation has been vulnerable groups specifically including Black people, and women. The Constitution commits the state to redress past injustices and protect women as a vulnerable group. The challenges include amongst others, expanded delivery of social services, job creation, poverty alleviation and development to enable these women to benefit from the national Constitution, which TWC, on behalf of these women tries to access through forging partnerships as outlined in Chapter 1.

b) Tensions and differences in participants' socio-economic contexts

There are key differences between the socio-economic contexts of the Black and Coloured women. The reason for this is that during Apartheid Black women's access to socio-economic benefits was largely determined by race. As indicated in Chapter 1 and 2, the newly elected democratic government inherited a country deeply divided and unequal as a result of a long history of racial discrimination and oppression. The vast majority of Black people in South Africa were discriminated against merely because of the colour of their skin. For the majority Apartheid meant the denial of the right to vote and other civil and political rights, like the right to freedom of speech and association. Also it meant the denial of socio-economic rights which included the dispossession of people from their land and housing, the underdevelopment of black communities, and discrimination in the quantity and quality of education, housing, health care and social security.

This history has resulted in the majority of the Black women in the sample still living in informal dwellings, with no running water and electricity and minimal familial links and support as all the Black women are not originally from Cape Town. The Black women generally have a lower level of education, a poorer grasp of English and Afrikaans (which are the dominant languages used in state institutions) and a larger number of dependents than the Coloured women.

These findings provide insights into and illustrate the multiple burdens of gender, race, class, poverty and the impact of historical inequities – the role women's histories and socio-economic conditions (poverty, lack of education, and skills,) play in constructing and shaping how these women live in the world.

This confirms the description of how these women live in townships and poor communities as outlined in Chapter 1.

When looking at women's shared vulnerabilities outlined below, there are similar indicators to those which emerge from their histories and socio economic contexts. These women have a range of different needs and priorities. These needs and priorities are only some among many other competing needs in South Africa at the present time, indicating the difficulty of implementing socio-economic rights.

2. LEVELS OF AWARENESS, UNDERSTANDING AND PRACTICE OF HEALTH RIGHTS

This section explores how participants learn, feel about and interpret human rights which includes how they learn about their rights to health and their views on the state's role in promoting human rights.

2.1. How Women Learn about their Rights

The women indicated that they predominantly learn about their rights in two ways that can be defined as 'informal' and 'non-formal', which is illustrative of Walters' (1998) notions of women's learning.

a) Informal learning:

All the women indicated they predominantly learn about human rights through informal, oral communication, which serves as a vital means of access to new information. All the women indicated they learn from pamphlets, posters, radio, TV, newspapers, and particularly community newspapers, which are viewed as an important source of human rights information as indicated by Bulelwa:

I mean you get the information from TV, even from newspapers. I like reading my community paper. When I was working I used to buy me a True Love [magazine]. When you read, at least you get [to learn] something.

Farhaana stated that:

For me it's like from posters, pamphlets and things like that. The radio is much better for people who don't read and who don't actually get out there. So, they will listen to the radio and the TV or so.

For all the women, oral communication is seen as a key way of learning. Some learn from their partners, other members in their communities and many from

within TWC. Some of the women see the TWC coordinator, Gugu, as a key conduit of information and the women trust her and feel she *'knows'* more than them about human rights.

Like my husband will maybe tell me. Or if I have a problem then I will talk to Gugu and she will say to me, "You have a right to do this or that".

I hear that you have got a right from people [in the community] where I live.

I got to know [about my rights] through The Women's Circle. It's a constant thing in The Women's Circle. So when somebody has a problem we will then explain to them that this can't happen to you because you have a right to this and then we will explain that right to that person.

If I didn't involve myself with The Women's Circle, I would never have known about my rights. I would just be sitting with the problem.

However sometimes the women's needs are not met as the information they receive is not enough or always helpful. For example, as stated by Bulelwa. *They say by now that you've got a right but when I go there, it's not like that.* Bulelwa previously indicated that she is an avid reader of magazines and newspapers as well as using her local community network to gain access to information. However, the information gained in this instance was not enough to enable her to access her rights. This could be due to various factors. One possible explanation is that popular media and people who act as key informants could not necessarily provide her with enough or reliable information to adequately assist and support her when she experienced a human rights challenge.

Notably, none of the women spoke about receiving information from healthcare professionals around their rights, which I discuss further below.

The study shows that popular media and community informants appear to be important sources of information. However, the findings imply that there is not enough reliable, relevant information and that a need exists to build a firm knowledge base within communities to ensure access to relevant, reliable information on what human rights entail.

b) Non-formal learning

At the time of the research, some of the women had participated in the focus group discussion around the UCT health rights pamphlets. One was involved in

a community based healthcare training programme. For those who mentioned it, added understanding around their health rights was as a direct consequence of their involvement in the two abovementioned, non-formal learning activities.

Ayanda says that attending the UCT focus group around the health rights pamphlets helped her to acquire knowledge which assisted in building her confidence. This enabled her to ask the doctor questions relating to her health which she would never have done before:

I am so happy because I know what I must do, because I've got [knowledge about] my rights. Before when I was sick I never asked the doctor because I was scared to ask what's wrong with me.

Ayanda further narrates how her new knowledge assisted her in asserting her right to information within the public healthcare setting:

At the clinic, every time, my folder goes missing and it has created a problem for me for almost a year now, because I need my folder for when I must get my grant, you see. Before I was scared to talk to the doctor and I just sat with the problem. Then I came to the workshop. After that workshop I went to my doctor and I explained to the doctor. The doctor went with the new folder and came back with my old folder and he said, "Look here's your folder". He took the papers out of the new one, put it in the old one and destroyed that one. It was very good for me and I was feeling so nice that day. I say thank God for that workshop.

Ayanda has effectively used her learning to change her own behaviour which hampered access to her health rights previously. Ayanda's experience however contrasts with Dorah's experience. After attending the same focus group discussion Dorah says she knows and understands what her health rights are, but still feels unsure whether she knows enough as she says that she is '*still learning*' about her rights. Dorah's comment suggests that even though she has acquired new knowledge she may lack confidence which may serve to silence her voice and prevent her from asserting her health rights in certain situations.

Both Dorah and Ayanda's comments indicate that content knowledge around health rights enables them to understand and interpret their rights. However information alone does not always provide them with the ability to engage differently at this stage. Uncertainty and lack of confidence around their grasp of some of the concepts and power dynamics may create a barrier when trying to assert their rights in certain situations.

The findings above suggest that learning about human rights has to be seen in its social context. In particular situations, certain behaviours may not conventionally be regarded or perceived as acceptable and would create difficulty for women in claiming their rights. Thus human rights education has to ensure that not only do women know and understand their rights but have the confidence to articulate their knowledge as rights holders within a range of contexts.

2.2. How Women Feel about their Rights

When asked about how they feel about human rights, the women's feelings are best expressed by Bulelwa:

What will this world become if you don't have rights? You will feel that you are in prison.

Her underlying feelings suggest that merely knowing she has rights provide her with a sense of hope and liberation. Similarly, all the women view their rights to health as providing them with hope and they see the importance of asserting their rights and how human rights add value to their lives.

However, women can only assert their rights if they know what they are. For example Caroline narrates the story around her husband's death a few years earlier:

At the time when my husband Peter was knocked out of the train, nobody could do anything for me because I didn't know my rights. After a few years I found out what I can do [to get compensation] and now they are busy with the case. If you don't know your rights you are going to sit there where you are and people are going to walk over you.

Caroline's comment appears to indicate that it took her some time to discover that she was entitled to compensation before she could even start to seek recourse and redress for her husband's death. This suggests that Caroline operates within a context where access to her rights is not granted automatically, and she has to struggle to access information. Yet, access to information is a right itself enshrined in the Constitution.

2.3. Women's Interpretations of Human Rights

To understand how these women interpret human rights as a concept, I asked them to explain to me what they understood by the term. Some examples given were the following:

Unthundo bufazi, untoto bugazi. [You strike a woman, you strike a rock]

You've got the right to raise your voice. You've got the right to say no. You've got the right to refuse certain things. You've got the right to educate your children. You've got the right to stand up against the drug houses.

You have the right to education. You have free hospital care, especially the pregnant women. You have the right to say no to stuff that doesn't suit you.

Levels of awareness and understanding varied. Some of the women mostly drew on rhetoric or popular slogans. All the women were not necessarily able to name their rights, but they could explain what they meant. Some of them could not explain their rights beyond key messages or slogans. Others, gave examples such as rights to education, housing, employment, equality, information and healthcare. Dorah described the right to be treated with respect and dignity:

The nurses can't speak to me any which way that they want to.

Caroline explained the right to complain:

I just know that if I see something that is wrong then I have the right to say that it's wrong. Also I have to stand up for myself.

Helen described the right to equality:

They must treat us as one [and] the same. Not if they know me or if I'm going to give them money [I get treated first] and the one who has no money must sit there the whole day.

Another interesting observation was Gugu's comment in relation to her right to shelter as indicated below:

Fortunately for me I am privileged to have a place [brick and mortar house] to live. So yes, I have a right to a house.

The right to shelter is enshrined in the Constitution. Gugu's comment indicates that she knows she is entitled to the right to shelter, yet she views this entitlement as a privilege. Gugu's comment suggests that her underlying feelings are that she is fortunate to have a brick and mortar house when the vast majority of people live in informal shacks.

Within a context shaped by the concept of progressive realisation, which only serves to create an obligation on the state to realise socio-economic rights within available resources, this may serve to translate an entitlement into effectively being viewed as Gugu does, as a privilege. The finding suggests that such a context could serve to create competition for basic resources between and amongst vulnerable groups.

The findings indicate that in the short to medium term TWC should aim to build women's understandings of why they live the way they do and what creates these socio-economic inequalities. If the women's learning translates into lobbying and advocating for increased access to socio-economic benefits, this would possibly enable TWC to become a vehicle for social mobilisation in the long-term, which is a key challenge currently faced by TWC.

2.4. Women's Interpretations of their Rights to Health

All the women know they have health rights as a result of activities arising from TWCs relationship with UCT. However, rights to health were predominantly interpreted as a right to healthcare, because when I asked the women about their rights to health they kept on referring to their right of access to healthcare, as illustrated by Ayanda's previous quote, which impacted on the scope of the study as indicated in Chapter 1.

Only the Coordinator referred to the all encompassing definition of the right to health:

You have a right to be healthy, a right to healthcare, that when you go to clinics that you have a right to be treated with respect, right to have access to medicine, also that you have a right to live in a clean environment.

This awareness is due to the fact that at the time the coordinator was involved in discussions between TWC and UCT around the development of health and human rights programmes for civil society organisations. She was also the liaison person to ensure that TWC made a submission to the SAHRC and was therefore more informed about health and human rights than the other women.

As indicated earlier by Dorah, who had been part of the UCT focus group discussion, her content knowledge around health rights enables her to interpret and understand her rights yet does not translate into practice. This finding

suggests that women like Dorah need to learn about their rights in ways which take into consideration women's contexts and histories, and build women's voices to enable them to claim their rights, which is an objective this study wishes to explore.

2.5. Women's Views on the State's Role in Promoting Health Rights

According to the South African Constitution, the state has a legal obligation to ensure that health rights are promoted. To gauge whether the women know and understand this, I asked participants through a series of probes whether they thought the state has a role to play in promoting health rights and what they thought that role was.

None of the women were aware that the state has an obligation to promote health rights. Some of them were unsure of whether the state was playing a role or what the state's current role is. However, all the women felt the state should play a key role in health rights education as displayed by the examples below:

The government was put there by the people to look after the needs of the people and it [human rights education] is [clearly] a need.

Our husbands pay tax and our parents also paid tax and so on [for services to be provided by the state which should include human rights education].

We belong to the government. We can't do anything without the government. The government must help us [by providing human rights education] it will also be good for the government. It seems to me that the government's work will then be easier.

The above comments suggest that the women felt that they have voted into power a democratic government, who should look after the interests of citizens. They are tax-payers and based on this expect the state to deliver services which include health rights education. The idea of human rights making government's task '*easier*' suggests that women see a space for negotiation of rights if duty bearers and rights holders understand their roles and responsibilities. This would assist in avoiding adversarial behaviour. However working within the framework of democracy has created a tension between loyalty to a democratically elected state and holding the state to account for not fulfilling its obligations.

Some of the women appear to see a link between their political and civil rights and the state's responsibility to look after their interests in a democracy, which illustrate the views that civil and political as well as socio-economic rights are interrelated, interdependent and mutually supporting.

Some of them also recognise the link between good governance and citizenship education. However, none of the women articulated the state's role as an obligation but saw the state as having the '*power*' and the necessary resources to support human rights education. Furthermore opinions varied and when asked, there was no consensus about whether the state is doing enough to inform people about their rights.

Irrespective of the diverse responses, the women agreed that there is a need to improve people's access to human rights information. The state needs to play a key role in supporting the promotion of health rights in ways that enable people to understand and assert their rights. For example, Gugu stated:

It flashes across the TV every time, human right number 'soeveel', human right number ten, whatever. So they know the words, but our people don't understand the meaning behind those words. Or that it's not that words but there is something with that words that explains that right to you, that explains what it means to you and how it impacts on you as a person.

Further on in the interview she added:

I've never seen somebody pick up a pamphlet and say: 'Can you explain this to me?' What are you going to think about me if I tell you to explain this to me? I see it flashing around on TV, but I can honestly say it's not going to help. Yes, you will know the words but you won't know your rights.

Many of the women felt that human rights information was not filtering into communities in meaningful ways which build people's awareness, understanding and practice. Some of the women made the following recommendations in terms of creating more access to human rights information and ensuring that vulnerable people, within poorer communities, who need the information most are reached:

Bring it [human rights education] to the public, to communities, have open days informing people [about their rights]. It should be on the radio and on TV screens at day hospitals

[Human rights education should] start in the communities, start with the people. It should be at clinics, day hospitals even door to door campaigns. The cigarette people do it, why can't they [the state] do it about something as important as rights.

Educate people, but when I say educate, it has to be a process that people can relate to because when you think about the people, some of them cannot read and write and [therefore] will not take it in. So there needs to be other things involved like pictures, little role plays, that type of thing.

The women suggested that various media be used, oral as well as written. They felt that health rights education should be embarked upon within community and public healthcare contexts which include door to door campaigns to reach the most marginalized and vulnerable groups and that the promotion of health rights should be more than awareness raising but should be viewed as an educational process aimed at equipping women to invoke their rights.

The women's explanations suggest that there is a gap between knowing what rights they have and what these rights entail. For example none of them knew that the promotion of human rights is in itself an obligation of the state. They could explain what rights they had by drawing on popular messages, but did not know that the state was obligated to ensure access to their rights. The findings suggest that their level of awareness around their rights stands in contrast to their level of knowledge which possibly impacts on their understanding, interpretation and practice of these rights. Importantly, these findings point to a gap between awareness of human rights, health rights and the basic knowledge and understanding of the content and laws designed to protect them, which should be a key element of human rights education and is a core obligation of the state.

3. FACTORS WITHIN TWC WHICH ENABLE AWARENESS, UNDERSTANDING AND PRACTICE OF HEALTH RIGHTS

This section explores participants' motivations for becoming and remaining part of TWC as well as their experiences of TWC as a learning context.

3.1. Motivations for Becoming and Remaining Part of TWC

All of the women heard about TWC through their existing community networks. They became part of TWC for a variety of reasons: some because of their involvement in community activities, some to share their existing skills or to acquire new skills, others because they were unemployed and got tired of sitting at home. Caroline reported the following:

When my friend came to one of the computer training courses and heard about TWC, she thought, 'Ah, that is the right thing for Caroline because it involves communities.' So, she came to me, explained and so I got involved with The Women's Circle.

Bulelwa indicated:

I was looking for a place that can encourage me and help me to grow. When I went to the library, I met Aunty Joan [pseudonym] and I asked her about community based care. She said, 'You can come, we have been doing home based care [at TWC]. If you are interested you can come and listen.' So I went to the meeting, I listened and knew there were a lot of things that I could get here. I thought I am going to give this a chance rather than stay at home and being bored.

For the women who participated in this study, their reflections suggest that what was important to them was to acquire "useful" knowledge and practical skills. The majority of the women were open enough to state that they became members because they wanted to realise their own potential and participate for their own development around issues they regard as important, and not to learn about human rights, socio-economic rights or the right to health. Furthermore these findings which I will elaborate on, confirm that community informants are useful sources of information for the women.

3.2. Experiences of TWC

This section outlines participants' experiences of TWC as a learning context and includes their views on empowerment, the creation of space and building of voice, the coordinator as a facilitator of learning and the provision of non-formal learning opportunities

a) Feelings of empowerment

For all of the women, being involved in TWC is considered positive and beneficial. They narrate their feelings of satisfaction from being involved in TWC activities.

We are doing beads, we are doing fabric painting. Those things encourage me to go back to the people in my Circle, [and say], 'look at what we need, so that I can ask TWC.' They know how to make beads. They make that Aids brooches and that other piece. Now we are learning more here [at TWC]. We have learnt other sample [designs], nice things which we can go and sell to make money.

The kind of work that I am doing is good for the community. The people in the community used to say, 'We can't believe you don't get paid for that job because you are doing such a good job.' I love the work I do for the community, really because it works. I can see [the value] and people can see [the value in] what I am doing.

We learn a lot of things here, I didn't know I can do something with my hands like printing and painting the cloth, its something useful for me. Afterwards I thought, 'Yew! You can learn something at that place, you must keep on going. It's interesting man!' Even if I don't have money to come here, sometimes I borrow because I want to be here, to learn lots of things rather than you stay at home watching TV the whole day. It's not going to help.

The first thing, I can say is that I can see The Women's Circle is going to develop the women in my community. The Women's Circle has already started to help us with material that is why I have been teaching the women sewing with materials, cotton and everything. So I see The Women's Circle as being very important, even in future.

Today still, I am in awe when I think that even though I never thought of myself ever doing community work, I do it now and I enjoy it. My passion is to put things in place that would benefit out there.

Their reflections imply that TWC engenders trust in the women to deliver to their communities. This is an important aspect within an environment where there is limited access to resources. The women achieve recognition as role models within their communities as their activities serve to enhance their images, which contribute to their participation in TWC. They seem proud of themselves when they can share their knowledge and skills with community members. In this way, their involvement in TWCs activities invokes a feeling in the women that they are, as the coordinator states, being recognised for *"making a difference"*. This suggests that TWC is ideally located to act as a conduit for health rights education.

Respondents see learning contributing to them taking control of their lives and make the link between improving their lives, the betterment of their communities and by implication society, which add to their sense of empowerment³⁶ and the importance they derive from their activities.

Empowerment is used here to describe the women's personal development and sense of fulfilment gained through their involvement in TWC as they place great emphasis on this consequence. The women also express a sense of empowerment that comes from connecting with other women, assisting and supporting one another to empower themselves. All of them show a great

³⁶ As indicated in Chapter 2, the term empowerment is a weighted term, deeply embedded in rhetoric. However, I have chosen to use it here based on the adult education definition described earlier and because the women themselves often used it, reframing it in their own way, to describe their growth, development, progress and achievement.

excitement and enthusiasm for TWC's way of working and see this as leading to personal and community empowerment. The findings indicate positive views of the role and impact of TWC's activities in terms of providing access to socio-economic opportunities, skills and income generation for individual women as well as the communities they come from, unlike the state — though it is a state obligation. This provides an opportunity for TWC to lobby for the strengthening of partnerships with the state to ensure provision of health rights education and information.

b) The creation of space and building of voice

The creation of a space which allows for the building of women's voices appears to be a recurring theme and is considered by all the women to be a key measure of TWCs success. For example, the coordinator says that there is an understanding that the women are individuals, who in many cases lead lives fraught with difficulties and experiences of hardship.

[At TWC] We talk about creating a space where you can speak in your own voice, where you can be yourself, you don't have to pretend that you are something that you are not. You are basically just your normal self, we are all the same, we struggle with the same things [and] we go through the same challenges.

In her view TWC provides the women with the space and opportunity to meet and talk to other women and share their experiences. Being part of a group, the women develop relationships in which they feel 'safe' and in which ideas, views and experiences can be exchanged. The coordinator's view is supported by Farhaana, who says that her confidence was built as she was encouraged to develop a 'voice'. She identifies how her behaviour has changed as a result of increased confidence and she accredits TWC with this growth in confidence:

They let me open up and like I said, I don't really mingle [with others] and now I am learning to know people and how to mix with different people.

The findings illustrate the views that women learn through dialogue and sharing their experiences. TWC has effectively created the space where women can develop their confidence as a first step to building agency and facilitating the claiming of their rights in the long term.

Bulelwa says that a special relationship based on respect exists between and amongst the women in TWC, which enables the women to integrate across

barriers of age, culture and race. She contends that the coordinator plays a key role and is instrumental in creating this supportive environment.

I come here once a week, like today. You know what I like [about TWC], these people have got respect, especially the older people like Gugu, she treats people well and welcomes them in this house. First I was so nervous, but now I am free, especially since I am an African and she is a coloured, there is always that friction.

The women's comments suggest that TWC draws on informal and non-formal approaches and practices, although these approaches appear to be tacit ways of working. However, TWC approaches appear to emphasise the importance of collaborative learning relationships, where women encourage and support one another within the group. The women seem to gain skills to articulate their needs, discuss issues, develop a deeper understanding about the issues impacting on their lives and have compassion for other women affected in the same way.

c) The coordinator as a facilitator of learning

Gugu defines her role within TWC in terms that go well beyond that of "coordinator". She adopted a role for herself without any parameters of a job description, but rather guided by what she feels TWC needs. She says that as coordinator considerable skill in listening to and working with individual women to resolve problems and differences smoothly is important. Therefore, in her view, some knowledge of the women's day to day struggles is critical.

So, first you need to work with the women themselves. You need to know each person. You need to know what that person's needs are. You cannot only work with the person as that person has a family. Do we ever consider the families? We don't consider the families. If I am active in the Women's Circle, I have a life. So everyday I walk out and I go to The Women's Circle but at home I have a daughter who is unemployed, a son who is doing drugs and somebody else who has just dropped out of school lying at home.

Since she said she enjoys "*working with people and talking to them*", interacting with them on a personal basis comes naturally to her. She firmly believes that the success of TWC depends largely on the women's participation. In addition, she believes so strongly in the role of TWC that she often assumes the responsibility of actively recruiting members. The coordinator's efforts at recruitment can be positive as held by Ayanda recounts:

I gained something even the first time when I came and Gugu explained to us what The Women's Circle is and what The Women's Circle needs from the women. Then I thought no, I must go on with The Women's Circle.

Having lived in communities similar to which the women come from all her life, Gugu sees herself as an advocate for the women of TWC. She attempts to get women involved and to assist them in any way she can. By all accounts she goes beyond the call of duty to live up to the TWC requirements, albeit without any clearly articulated governance rules. She is one of the reasons why TWC has managed to access opportunities and resources, which the state has failed to provide.

d) Providing access to non-formal learning

Some of the women feel that recently they have been treated well by public healthcare practitioners and they attribute this to their participation in non-formal learning activities organised by TWC.

Helen feels that the nurses started treating people better when, after attending the health rights workshop, she mounted her copy of the Patients Rights Charter on the wall of the waiting room in the clinic.

Since the nurses saw the Patients' Rights Charter, they [the nurses] pretend to be nice to us now. Before, they didn't care about us. Now they're coming right slowly, slowly, slowly.

Gugu feels being more aware of her rights built her confidence, raised her expectations, and has made a difference in terms of how she engages within the public health context:

Now it's different because I am educated in my rights. So I have high expectations now. Before it was acceptance, I used to go and just say, 'Yes, yes, yes' to whatever. I would take my tablets and leave. Now, I'm more aware [of my rights] and the funny thing is it's something that you carry with you. I think when a person has grown then a person feels worthy.

The study demonstrates that through TWC non-formal learning programmes participants not only gain access to information and resources but learn about human rights such as respect and dignity (for other women and cultures) while performing other activities.

Secondly, participant histories may have had the impact of silencing their voices, but through engagement within TWC the women learn to develop

confidence and discover their voices, illustrating the value of learning within informal contexts.

4. BARRIERS TO AWARENESS, UNDERSTANDING AND PRACTICE OF HEALTH RIGHTS

This section outlines barriers to creating awareness, understanding and practice of health rights in relation to TWC as well as within the context of public healthcare facilities.

4.1. In Relation to TWC

Barriers to creating awareness, understanding and practice of health rights relate to participant motivations for becoming and remaining part of TWC, interpretations of TWCs programme of action, economic barriers in relation to participating in TWC activities and leadership and management within TWC.

a) Motivations for becoming and remaining part of TWC

As indicated above, all of the women became involved with TWC after they heard about TWC through their community networks and some had read the TWC brochure (See Appendix C).

The findings indicate that word of mouth and popular media like the TWC brochure are viewed as important sources of information for these women. However, the findings suggest that information received via word of mouth is not adequate as community informants only provide information they regard as important. For example, Bulelwa was informed that TWC provides home-based care training. Caroline was informed about the computer training and community development aspects of TWCs activities only. Yet, the TWC brochure states that TWC's aim is to *assist and support women as individuals and extensions of their communities to access their human rights*. However women with functional level literacy skills would not be able to easily interpret and understand the brochure. These could possibly be some of the reasons why they lack understanding of TWCs strategic aims and objectives, resulting in TWC acting as a localised vehicle for women seeking socio-economic benefits and opportunities.

b) Interpretations of TWC's programme of action

Currently, TWC acts as a conduit between the women's concerns and access to goods and services provided predominantly by NGOs and the state. TWC must do so, however, against the backdrop of a negative racialised history of residential segregation, discrimination and lack of access to resources.

Through a series of probes I asked the women to reflect on TWC's aims and objectives. The women mostly interpreted these as the activities they engage in on a daily basis and I discovered the following interpretations of the role the women see TWC playing in their own lives and their communities:

I put in a proposal through our Circle and it was supported. TWC is actually looking into it and buying dominoes, cards, balls and things like that. So yeah, viva for The Women's Circle.

We are busy with beading, fabric painting and I just love it and if there is something to be done in the community then we do it.

The Women's Circle has already helped us with material and cotton so that I can teach the women sewing and beading.

Only the coordinator's response reflects awareness of elements of human rights:

There are different things we do. One of it is educating people around their rights, how to access those rights and the responsibility that goes with those rights. The other thing is to empower women.

Excluding the coordinator's view, the activities they express do not focus on human rights. They do not express attempts to challenge the state and transform structures nor do they make a direct link between human rights and their daily activities. They mostly referred to the socio-economic impacts and benefits and seem to value access to resources, skills development and the (social) activities. The women view major gains to be access to opportunities to improve their livelihoods, which suggests several things. Firstly, their level of social and economic development and quality of life is low. Secondly, access to socio-economic services and resources still largely remain out of their reach. Moreover, they do not see their lack of access to socio-economic services and opportunities as a human rights issue; they do not see the links between their poverty levels and the policies of the state and appear to accept their positions in life.

The findings show that at this stage of the programmes development, TWC has successfully facilitated access to a range of opportunities and resources; and started the process of building women's awareness, understanding and positive health rights practices. However, at this stage, the women still accept their state of low socio-economic development and do not lobby or challenge the state to change this. TWC therefore needs to continue to build individual, and more importantly, collective agency through facilitated education programmes around a range of human rights issues.

c) Economic barriers relating to participating in TWC activities

One of the most common barriers to successfully participating in TWC and other human rights learning activities is the economic difficulties the women experience.

For example, Elaine said:

Sometimes, some of the women haven't even got transport [monies] to come to the training. That is why in future we need to do some training in the communities, near to where the women live.

Helen receives a stipend from the Department of Health, whilst participating in a community-based healthcare training programme. Helen expressed concern that she has to use some of the monies to care for her patients.

I'm doing home based care in the community. We are working with sick people. We help them. Some of them have nobody to look after them – everybody [in the home] is working. So, we go there in the mornings and when we get there, maybe the patient has got no porridge, no water to bath and sometimes you find that there is no paraffin in the stove. If she [the patient] is near to where I live, I go fetch warm water at my house and take it there. I only get R250 a week, on the fifteenth of the month and from that money my children must also eat.

All the women, except for the coordinator, the administrative assistant and the domestic worker, participate voluntarily and are not paid for the time they devote to attending meetings, training activities or participating in community projects. Neither are they paid when they participate in lobbying and advocacy activities.³⁷ Some of these women work extra-long hours and experience difficulties when they travel to participate in activities outside their communities. Though they largely accept the unpaid nature of TWC work, the women in

³⁷ Busfares are paid by TWC when the women attend coordinators meetings or have to travel to workshops.

various ways expressed concern about the financial burden they face, which increases their workload and strains their already scarce financial resources.

d) Leadership and management within TWC

As indicated the coordinator has had to adopt a role without the parameters of a job description, but guided by what she feels TWC needs. She believes so strongly in the role of TWC that she often assumes the responsibility of actively recruiting TWC members and coordinators of community-based Circles. This area is in fact a very grey one, fraught with potential conflict as there are no guidelines on how to select coordinators of Circles or how to deal with a continuous intake of new members, which impacts on governance and growth of TWC. This finding indicates that TWC needs to ensure that roles, responsibilities and accountabilities are clearly spelt out to ensure good governance to assist and support the growth of TWC's programme of action.

4.2. Within the Context of Public Healthcare Institutions

As indicated most women interpreted the right to health as the right of access to healthcare and when probed in terms of their practice they mostly referred to public healthcare delivery. This interpretation is partly due to lack of understanding but also because of the contentious nature of public healthcare contexts which are a basic and key site for health rights claims. Therefore this section explores how the women react when attending public healthcare facilities and what facilitates or prevents them accessing their rights to health within these contexts.

Some caution is necessary in interpreting the women's contributions as their reflections may reveal attitudes towards public healthcare staff rather than actual 'facts' and/or there may be a tendency to exaggerate the negatives and underplay the positives. However, allowing for these limitations, the interview process suggests the following responses

a) Feelings of powerlessness

What struck me as I contemplated the women's responses were their feelings of powerlessness when faced with the current reality of attending public healthcare facilities. The women largely feel that the context of local hospitals and clinics

has not supported attempts at asserting health rights. Though the women's experiences of powerlessness vary, the majority are highly frustrated and repeatedly refer to and are highly critical of the way the nursing staff treat them.

I can say that the doctors are fine but some of the nurses, ooh, even if you are sick they just call your name and you have to struggle on your own to stand up. Yet, they will shout and shout, it's not right - I can say the doctors are doing fine but the nurses!

I just want them to treat me like I'm a human being and to have some respect, mainly I would say to have some respect because at some of our day hospitals people don't have any respect for you, especially the nurses. If there are a lot of patients and they have given x amount of numbers for the day [and you do not receive a number] even if you are really sick, they chase you away like a dog. That's not on and it makes me very angry.

When you want to see the doctor you must go to the nurse, but you must wait until she is finished talking or drinking her tea. Their tea times are from ten o'clock, but they carry on until eleven, past eleven, you don't know how many hours they take for tea. They are supposed to get thirty minutes for tea and one hour for lunch. But they take an hour. And for lunch they take two hours. That's not right, it's not fair because the person who is sick can die there and then only will they get up.

[At the hospitals] Because we are poor, because we have nothing, because we think that we are nothing, they treat us like nothing.

Some of the women reflected on how doctors relate to them within the patient doctor consultation process:

When you pay for services, automatically because you are paying, it's so easy, you can say what you want. You can say what is not agreeing with you and what is agreeing with you. But when it's free, there is so much shame that goes with free and I don't think many people realise how much shame goes with free. It holds you back from saying what you really want to say. It holds you back from asking, 'What are these tablets for? What does it do to my body?' How many of us ask 'What does this tablet do to our bodies?' We don't because we accept and why do we accept most of the time? Because it's free, I can't afford to pay so I have to go with the flow.

The doctor will look at you if you are a chronic patient and just jot down another lot of medicine for you for the next month.

They say that the doctor doesn't understand Afrikaans very well. And most of our people are Afrikaans speaking. Like our neighbour went and she told him that she doesn't speak English, she speaks Afrikaans and he didn't even call in another sister or a nurse to explain to him, he just did his own thing. She tried to use her broken English to explain to him what is wrong but when she got home, he had given her the wrong pills.

You sit there with the doctor [who cannot speak Xhosa]. The doctor goes out and says to another patient, come, you come and help me here [to translate].

The women's reflections suggest that imbalances of power persistently result from a lack of equality and respect within public healthcare settings. The women

feel marginalised and powerless to confront problems which in more equitable relationships they would never allow to continue. Such negative interactions cause a great degree of stress and impact on how they engage within the institution.

b) The shame of free public healthcare

For the women interviewed, negative connotations are attached to the notion of free public healthcare. When attending local clinics or hospitals the women feel healthcare professionals generalise and stereotype them, are unsympathetic to their needs; they are not important enough to be spent time with because they are poor and healthcare is free. This suggests that women are most likely to feel marginalised when they are treated badly and when negative judgments are made about them because they are poor.

c) Lack of respect

All of the women see the component of respect as a necessary part of healthcare but feel that public healthcare professionals treat them with a lack of respect. As I only interviewed women, I expected issues relating to gender discrimination to arise, however this was not the case. Probing whether women are treated differently, the majority indicated that there was a general lack of respect for all people attending their local hospitals or clinics, not only for women.

d) Not being seen as a person with an identity

Linked to the concept of respect is the idea of being seen as important in the process and being listened to and heard by healthcare professionals. The women are aware that some public healthcare professionals struggle when having to deal with diverse communities and are sometimes unable to communicate with patients in their own languages, leading to situations where other patients have to translate on their behalf.

However, when healthcare practitioners do not engage patients, or are incapable of doing so, due to language barriers around something as important as their healthcare, the women feel that this shows a lack of understanding and consideration for them.

The women appear to be aware that their position in society makes them behave in particular ways. They struggle with these internalized constructs of reality which result in low self-esteem and lack of confidence. The women's feelings of powerlessness, their lack of confidence and control stem from healthcare professionals' perceptions of them. The women's perceptions of how nursing staff define and make distinctions between public and private health care patients become tools of power which dictate and shape how they make meaning and engage within the public healthcare context.

e) Other institutional constraints

Some of the women feel that previously white institutions are still better resourced than clinics in their local communities. In their view this still reflects an inequitable distribution of resources and perpetuates the imbalances of the past. Ayanda commented on the fact that hospitals in predominantly black communities are still not as well resourced as hospitals in predominantly white communities.

So, I hope even in hospitals in our communities things must be the same. It mustn't be because that hospital there belongs to the whites or to whatever. It must be the same treatment.

However, the women seem accepting of the situation, though they are aware of and recognise the inequitable distribution of resources. This seems to be linked to the lack of functioning complaints mechanisms. Though complaints mechanisms should be available in all hospitals and clinics, the majority of the women indicate that they do not complain about the poor healthcare services they receive or when they feel their rights are violated. When asked what stops them from complaining or from their complaints being heard respondents indicated the following reasons:

Let me tell you something, it's not even worth it [to complain]. You have these notices up saying, that if you are not happy, you can go to sister whatever on top. Does it make any difference? It doesn't, that is why people don't bother to complain.

What do patients do, they stand in the middle of the day hospital and they vent their frustrations. And then what is the response? 'You're rude, go home, you're not being helped today'. But have you ever thought what causes that frustration? You have to stand in a line, yet suddenly when you think you are going to be helped, there they [nurses] go off to tea. Those things, its little things but it's a disrespect to people, yet they are being paid.

Well there is a box but I don't know, the people don't put their comments down. I don't think its helping. They can throw those papers away.

There is a sister in charge at the day hospital and there is a box where you can put your complaints in but like I say, it has never worked, so what's the use complaining to them.

Sometimes you sit at the day hospital and then you know there is something wrong but you are too scared to say something because you are scared the nurses are going to chase you away or something like that. So you just sit there all day, too scared to say anything because you need that medication.

Furthermore the study suggests that both the women and public healthcare practitioners' histories and backgrounds play a role in terms of how they currently behave within the public healthcare contexts. Public healthcare contexts have traditionally held very narrow views of public healthcare service provision. These histories may impact negatively on service provision and what women view as appropriate behaviour within the healthcare context, perpetuating the embedded power dynamics, which creates barriers to accessing their health rights.

f) Lack of functional institutional mechanisms

The women share the common assumption that institutional mechanisms either do not work, do not exist or the nurses have the power to facilitate or deny access. They are powerless in dealing with the nurses, feeling that their actions are governed by them as the people who inhabit the 'power' structures within healthcare facilities. They also fear if they complain they will be turned away the next time they come or that even if they complain nothing will be done and they are wasting their time. Some of the women indicated they do not know where to complain, or do not trust that their voices will be heard.

Furthermore, those who complained did not see any sustainable improvements. Caroline says that only after she went to the media, who published the story, did services improve:

Yes, we do complain and at first they didn't do anything about it. But there was this one incident where this lady actually phoned me, and told me to phone the newspapers to come to the day hospital because of the way things are happening at the day hospital. They actually did an interview with the newspaper and the service after that was a little bit better.

g) Attitudes of healthcare practitioners

The women see knowing their rights as giving them an opportunity to make choices that move them away from the feeling of powerlessness. Yet, healthcare practitioners' attitudes and behaviours and the lack of institutional structures to take their complaints forward discourage them and make them feel as if there is nothing they can do to change the situation, reinforcing the embedded power relations which negatively affect women's rights to health, as Ayanda stated:

In our hospitals in the community, if you say to the nurse for example, 'Nurse I will go and report you to the sister in charge'. That nurse will say to you, 'You can go, she can come I don't care about that'. So there must be somebody strict in that position because they are not scared of anything, they do what they like, they don't care.

Human rights within the public healthcare context hold contradictions for these women. From one perspective, women gain power as they continue to learn about their rights, which leads them to take action and challenge embedded power relations within public healthcare contexts.

In another perspective they feel powerless within the institutional context when dealing with healthcare professionals because of the lack of institutional mechanisms which prevent their voices being heard. However, the women are not unsympathetic to the plight of public healthcare staff as indicated by Helen:

Sometimes, I can't blame them. They work with high stress [levels] because they pile them with clients, you see. Sometimes the doctor works nightshift, now he must still work during the day, which adds to his stress.

Elaine said that facilities in communities are run down and dirty though staff are employed to ensure maintenance of these facilities.

Mostly the clinics and hospitals in our communities are very dirty. There are flies around, they smell. Even if you go to the toilet, it's very dirty yet the government employs people to do that work, but they don't do it properly.

The women's overall impressions of attending public hospitals or clinics are that the culture is extremely unhelpful and unfriendly. It is an environment in which asserting one's rights is undervalued and the context subjugates the women's individual agency. The way the women represent themselves in relation to the context in which they act, and the way they interact with people in these domains, is an integral factor to how women practice their rights. The findings

suggest that the struggles the women go through to access their health rights and the ways they see and view themselves, seem to be an important contributing factor in silencing them or acting out certain patterns of behaviour.

The women's behaviour in public healthcare contexts represents more than mere conditioned responses on the part of women in society and the learning context. This behaviour represents the way women have been socialised, to have "common assumptions" about how they ought to behave within public healthcare institutions, dominated by healthcare professionals as "the knowers" or holders of knowledge.

The context of local hospitals and clinics has not supported attempts at asserting health rights in the past. Histories and backgrounds determine how women operate within their current realities, which is a barrier to them accessing their rights

Although the Constitution, the Batho Pele Principles and the Patients Rights Charter protect women from the abovementioned violations, women 'historically situated' in this environment generally have not had the power to bring change and are generally tolerant of the inequitable relationships. Additionally the women's lack of participation in the liberation struggle, which is well known for building women's agency, affects their current agency and results in a lack of confidence and an inability to confront structures with embedded power relations such as public healthcare facilities. This is an aspect which must be addressed in women's education as outlined in the literature review.

Chapter 5 includes the analysis and discussion of the findings as laid out in this chapter as well as the conclusions and recommendations of the study.

CHAPTER 5: DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

*“When a person has grown then a person feels worthy”
(Gugu quoted on p 66)*

INTRODUCTION

Chapter 5 interprets and analyses the main themes in the findings of the study. As indicated in the literature review, understanding how women live and exist in the world and how this relates to awareness, understanding and practice of their health rights is often overlooked in research studies (Shifvji, 2002). Therefore this study explored the impact of the socio-economic context on women's learning in relation to their health rights as a potential gap within current health rights research.

1. OVERVIEW OF FINDINGS: AWARENESS, UNDERSTANDING AND PRACTICE OF HEALTH RIGHTS

An overview of the findings presented in Chapter 4 led to the observations that women's levels of awareness, understanding and practice of health rights differed but they are willing to assert their rights. Patterns emerged in relation to women's histories, socio-economic factors and the contexts they operate in such as TWC and public healthcare facilities which act as either facilitators or barriers to their health rights claims.

The findings indicate that paying attention to women's histories and how they experience the learning context, as learners, is important and can enhance our understanding of how to improve awareness, understanding and practice of health rights.

The findings illustrate and advance the views within the domain of health, human rights and adult education as outlined in Chapter 2.

2. DISCUSSION OF THE FINDINGS

This study drew on multiple domains bearing on the findings provided in the next sections.

As indicated in the problem statement in Chapter 1, despite more than fourteen years of formal democracy, South Africa remains a country with profound inequalities in relation to access and distribution of resources. Evidence to date which include London (2003, 2004); Holtman et al. (2004) and Thomas and London (2006) point to the importance of knowing and understanding health rights on the part of communities most vulnerable to the violation of these rights as key to redressing social inequalities.

However, translating awareness and understanding into practice is fraught with difficulties and obstacles. Thus, understanding these difficulties and obstacles may explain why, despite having a constitutional framework that promotes the right to health, ordinary South Africans still struggle to realise these rights.

This qualitative research study therefore aimed to explore and provide a deeper understanding of factors which act as barriers or facilitators to women's health rights and identify what kinds of strategies are most effective in overcoming these obstacles.

2.1. Women's Histories, Life Experiences and Socio-Economic Contexts

The study illuminates a range of factors and constraints which are rooted in women's histories, experiences and socio-economic conditions, which impact on their levels of awareness, understanding and practice of health rights. These factors and constraints include poverty, unemployment, low levels of education and lack of market related skills, which result in women bearing the brunt of poverty with little access to resources and skills to change their situations.

These impacts and vulnerabilities are evident in the findings outlined in Chapter 4 which illustrate key elements of women's lack of control and autonomy over their health and lives, limited access to socio-economic resources and opportunities, as well as patterns of gendered division of labour.

The study illustrates the lack of alignment between the rights to health of vulnerable groups as enshrined in the South African Constitution and the Bill of Rights (1996) and the realities of these women, making it difficult for them to maximise use of the political space that has opened up to them since South Africa became a democracy in 1994. These features are consistent with that

reported by Ismail (2006), Essof (2005) and Walters (1998) in the Feminist literature and the daily lived realities of these women as outlined in Chapter 4.

2.2. The Impact of Socio-Economic Factors

As indicated, all the respondents, because they have limited access to socio-economic benefits and resources, predominantly learn about their health rights informally and through a variety of sources.

a) *The value of popular education*

The findings indicate that popular media (radio, TV, pamphlets and newspapers) are viewed as important sources of information and play a key role in creating awareness of human rights. However, popular messages contained in these media do not necessarily enable the women to assert their rights as the messages are limited to key phrases which are not enough for women to understand what their rights entail. The result is that popular media campaigns have limited impact as they do not provide enough content knowledge or outline clearly where women can seek help or complain if their rights are violated. Neither nor do these media messages outline the state's obligations in relation to health rights, resulting in the vague understanding of health rights. This vagueness translates into women being aware but not being sure, not knowing, not understanding or necessarily recognising when their rights are violated. Nor have they the skills and sense of power and control to assert these rights when they are infringed upon.

b) *The value of oral communication*

The study found that people who act as the women's key informants in terms of their rights are people they come into daily contact with, which include their husbands, other women within TWC and women in their communities. These informants do not necessarily have enough information themselves to provide the necessary support around health rights. However, community informants act as an important information source which can shape or constrain women's behaviour, as they trust them.

The promotion of health rights and access to information is a core obligation of the state enshrined in the South African Constitution, yet messages and

opportunities for appropriate learning, education and media which engage these women in a consciousness-raising process (Weiler, 1991; Walters, 1998) in relation to their health rights is sadly lacking. These women are forced to learn incidentally and in informal ways due to a low standard of education, occupational status, and income levels (Walters, 1998) and have little option but to rely and trust community informants because they share similar challenges and experiences. This finding is consistent with Thompson (2000) and Luttrell's (1988) views in the Feminist literature.

2.3. How Socio-Economic Factors Influence Women's Motivations to Learn

During Apartheid, although thousands of women participated in political activities at various times, none of the respondents were active in any Feminist or political movement. Nor do their narratives reflect any involvement in current political or Feminist activities, suggesting that the women who participated in this study are not motivated by a Feminist or a political agenda. Patterns and motives observed between and amongst the women which encourage them to participate in TWC activities include attempts to acquire resources, knowledge and skills to lift themselves out of poverty and the daily hardships they encounter which suggests that their motivations to learn are related to improving their lives and the lives of their families.

This finding is consistent with Ismail's (2006) conclusion in a similar study she conducted which involved women and their housing rights. Ismail (2006) argues that women do not necessarily get involved in development activities for Feminist or political reasons, but are motivated to learn and participate in activities, driven by the interests of their children and improving their lives. She identifies this as one of the main factors influencing women's participation in development activities, a view expressed by a number of gender activists which include Molyneux (1985) Moser (1993) and Thompson (2000) in a development context, which my findings illustrate. Women's histories and socio-economic factors therefore play an important role in terms of how, where and what they learn in relation to human and health rights as this has implications for their practice of their human rights outlined below.

2.4. Women's Experiences within TWC

The findings indicate that within TWC, women learn in non-formal and informal ways (Walters, 1998) which include dialogue and sharing information while going about their daily activities.

a) *The value of non-formal learning*

Most non-formal learning within TWC is geared towards developing skills and acquiring resources to manage projects within communities, which has impacted on the kind of learning that happens within TWC. This means that learning is primarily driven and geared towards skills development and resource acquisition and not aimed at developing awareness, understanding or human rights practices. Within TWC, learning for these women relate directly to where they are located in society, not because of any political motivations to challenge inherent power relations or necessarily to seek social transformation.

These women, at this stage of TWC's development, do not see the link between their daily struggles, local actions and a broader social transformation agenda; they do not actively lobby the state for their rights as a vulnerable group or for their health rights.

Despite the constraints that restrict their learning, the participants reported positive experiences arising from their learning within TWC, such as enjoying the social activities, acquiring of market related skills and building of confidence and a sense of empowerment.

London (2004), in the health and human rights tradition, contends that human rights are about power relations and that empowerment is not simply about income. Consistent with the Feminist literature (Ismail, 2006; Walters 1998) he argues that it is about building individual and collective agency.

For some of the women who mentioned it, they had been both empowered and disempowered by participation in non-formal learning activities about health rights. The women's narratives indicate that useful health rights information was obtained which built their capacity and enabled some of them to raise their voices, question public healthcare professionals and access information and

healthcare. Some of the women indicated that knowing their rights has strengthened their agency. Gugu narrated how her confidence to claim her rights within the public healthcare context was built because she knows she has health rights. For some of the women this is only the beginning of their process of learning and has not resulted in mobilisation or transformative action (Mezirow, 1991), as they indicated that they were still learning and did not necessarily have the confidence to raise their voices.

This illustrates London's (2003) view that human rights can serve to strengthen vulnerable people's agency as rights holders and enable them to negotiate and hold duty bearers accountable for ensuring access to health rights. In this way human rights enable vulnerable people to redress power imbalances and access their rights to health without necessarily using adversarial approaches.

b) *The importance of the learning context*

The significance of women connecting with one another and the value of learning in a group is illustrated by the women's narratives as they describe how they help and support each other by listening, understanding and teaching one another and through this experience build their confidence. The women assist each other, develop relationships in which they feel safe in the learning environment, and in which ideas and views are exchanged. Some of the women also stated that a special type of relationship developed between and amongst them and cited the value and importance of this in allowing for cultural, racial and religious integration and diversification. Through collaboration the women are able to reflect on what they know and do not know. This allows them to share ideas and experiences, which assist them in solving problems and often finding what Mezirow (1994) terms 'new solutions', not only within TWC but also in terms of their own development (building of confidence) which impact on their personal lives.

The women within TWC view themselves as a community (of learners) and learn as a group. Learning is embedded in TWC's day to day operations in the way the women work together, with the Coordinator guiding the learning, enabling them to learn from one another. In this process the women themselves act as key resources, helping one another to make sense of situations as they

draw on their local knowledge. Thus, the kind of learning which is affirmed within TWC is learning which leads to knowledge and understanding, enabling the women to improve their everyday lives.

The study reflect notions of Lave and Wenger's (1991) 'Community of Practice' model, illustrate Walters (1998) view on non-formal learning, substantiate Hayes (2000) and Belenky et al. (1986) views on collaborative learning and is consistent with Ismail's (2006) study on women's learning within a group and that connecting with one another is an important element in the learning context. TWC can therefore be viewed as both a site of learning for the women engaged in its activities as well as a source of new and useful knowledge. However, Belenky et al. (1986) caution against assuming that all women learn through connection with other women in a group situation.

c) *The value of learning in a group*

The women's views of empowerment and building of voice are key indicators of successful informal learning within TWC. In this way the women develop confidence and 'find their voices'. Their narratives indicate that these are regarded as important, first steps in confronting the challenges in their daily lives and for them important learning occurs informally and incidentally.

The women's use of the term empowerment can be equated with the notions of personal development and transformative learning as defined by Mezirow (1991; 1994). Furthermore, the way they learn illustrates Walters' (1998) notion of informal learning, and the women's views on finding their voices and articulating their feelings illustrate the Belenky et al. (1986) and Gilligan (1993) views on the importance of building women's voices in the Feminist literature.

The findings illustrate the value of informal learning which enables women to learn incidentally about health rights such as respect, dignity, understanding of diversity and difference, as well as build their confidence and enable them to use their voices which translates into a sense of 'empowerment'. This is consistent with Sen (1990) in the international development literature that argues for the building of women's capacities through education and social reforms to enable the removal of various 'unfreedoms' which women suffer.

e) *The role of the coordinator as a facilitator of learning*

The co-ordinator is viewed as instrumental in creating a supportive learning environment within TWC. Her growing confidence and capacity in leading TWC has come from integrating the voices of the other women with her own experiences, illustrating what Belenky et al. (1986:121) refer to as *connected knowing* (which) *involves feeling, because it is rooted in relationship; but it also involves thought.*

As indicated in Chapter 4, the coordinator embodies the kind of learning that is valued within TWC, i.e. learning which leads to socio-economic benefits. This has had a profound influence on the direction that learning has taken within the organisation. The direct result of this is that no further leadership capacity has been built within the organisation. The coordinator remains the only full-time employee, with the women viewing her as the one with the most useful knowledge, particularly in relation to health rights.

This finding illustrates not only the value of learning but also the critiques within the Feminist literature by Young-Jahengeer (2003); Walters (1998); Weiler (1991) and Ismail (2006) of adult education perspectives which neglect to take into account issues of power and power relations within learning contexts as well as the broader, historical and structural relations of power at a societal level. Ismail (2006) applies this critique to the Community of Practice model in her study and argues that these power relations may be replicated within the dynamics of any community of practice. Ismail (2006) further argues that this is not unusual as there is a tension between *using collective pedagogy and democratic organisational methods and practices to attain individual goods* (Ismail, 2006: 259-260).

2.5. *Impact of Women's Histories on Learning in TWC*

The study revealed that the majority of the women have a limited understanding of TWCs aims and objectives and reflected an operational rather than a strategic understanding of TWC's activities. They also have a conventional approach to human rights, which possibly has a lot to do with their experiences and backgrounds. They do link their poor socio-economic positions to their lack of access to health rights. However, functional literacy levels and limited access

to health rights information outside of popular media, which only highlight key messages and lack content, has resulted in an inadequate understanding of their rights which acts as a barrier to TWC's ability to act as a vehicle for social change. This has resulted in TWC becoming a localised vehicle seeking to address poverty related issues of women on the ground, instead of adopting an agenda for social transformation. This contradiction is a key tension highlighted within the development literature by Walters (1998), who argues that knowledge and popular methodologies do not necessarily mobilise people to act and that *this contradiction is at the heart of radical educational practice* (Walters, 1989: 294).

These findings acknowledge the successes and challenges encountered by TWC as a programme and by the women involved in TWC. Furthermore, they identify factors which may inhibit or facilitate access to health rights as well as lessons to improve practice within TWC and UCT to build women's capacity to claim their rights.

2.6. Impact of Women's Histories on Learning in Public Healthcare Contexts

The study found that a parallel situation within community contexts exists within public healthcare institutions in relation to the impact of women's histories on how and what they learn about their health rights, the importance of public healthcare practitioners as facilitators of women's learning, public healthcare contexts as sites of learning and the importance of building women's individual and collective agencies to invoke their rights to health.

b) The role of public healthcare professionals as facilitators of learning

The women's narratives demonstrate that the notion of health rights is known by public healthcare professionals, but is not necessarily recognised and acknowledged by those people involved in public healthcare service delivery. The women generally do not trust public healthcare staff. They indicated that infringement of health rights within these contexts are neither monitored nor acted against, leaving most of the women feeling powerless and marginalised when attending a public healthcare facility.

This finding is consistent with other research into patients' rights in South Africa by Holtman et al. (2004) and Thomas and London (2006) who argue that women continue to face a range of challenges when trying to access public healthcare services, with one of the key challenges being public healthcare practitioners, who have traditionally been viewed as holders of knowledge and play a powerful role in either facilitating or denying access to healthcare.

c) *The role of informal learning*

For some of the women there is intense shame associated with free healthcare. Many of them feel that since they are getting free healthcare, they are not taken seriously; if they had to pay they think they would receive good service and public healthcare staff would treat them better. Some of the women indicated that they do not have access to their personal health information, staff cannot relate to them in their own language and treat them with a lack of respect; yet they do not complain. Much of the women's silence is a consequence of their fear of being denied access to healthcare or being scolded, having seen this happen to others and dreading the same would happen to them.

The literature Rowlands (1998) and Parpart (2000) cited in Ismail (2006) caution us that learning and knowledge are embedded in social contexts and are attached to different power positions. This finding is consistent with Holtman et al. (2004) who claim public healthcare professionals' control over knowledge serves to reinforce power structures and hierarchies.

d) *The value of non-formal learning*

The study indicates that for some of the women content knowledge around health rights enables them to understand and interpret their rights but not claim them. Information alone does not always provide them with the ability to engage differently at this stage. Uncertainty and lack of confidence around their grasp of some of the concepts and power dynamics create barriers and silence their voices, preventing them from asserting their health rights. However others' learning built their confidence and they effectively used their learning to negotiate access to their health rights. Thus learning must enable women to develop a voice as the starting point to assist in accessing rights to health.

Thus the recommendation by Holtman et al. (2004) that education programmes need to be developed makes sense only if the contexts of public healthcare facilities are addressed or learning may not necessarily translate into women accessing their rights to health. As indicated, this view is consistent with Ismail (2006) who argues that information and knowledge can mobilise people to act; however the structures in society have to change, which is evidenced in this study by some of the women's attempts to access their rights within the public healthcare context, which is unsupportive of health rights claim due to embedded power relations. Such relations sometimes result in adversarial approaches as women become frustrated due to the unhelpful nature of public healthcare contexts and staff attitudes.

These findings are consistent with London's (2004) view that educating women around their health rights must support negotiation of health rights, which is more suited to addressing vulnerable people's health inequalities than traditional approaches to health and healthcare. Furthermore, they London's (2003) view that human rights can serve to strengthen vulnerable people's agency as rights holders and enable them to negotiate and hold duty bearers accountable for ensuring access to health rights.

3. CONCLUSIONS

As indicated in the research questions, this study explored a relatively new subject, vulnerable women's awareness, understanding and practice of their rights to health within a civil society context.

In response to the sub-question (a) is being aware and understanding that they have health rights enough to enable these women to invoke their rights (practice) and overcome obstacles in relation to health inequalities? The study found that being aware and understanding health rights is not enough to overcome factors driving inequalities or to ensure access to health rights for the women who participated in this study.

In response to the sub-question (b) what kinds of adult learning strategies are most effective in overcoming obstacles and facilitating access to health rights? This study to some extent validates and illustrates the literature in Chapter 2 as

there is significant evidence that adult learning methods and approaches, particularly those that intersect with Feminist methodologies such as Ismail (2006) Walters (1998) and Belenky et al. (1986) which illuminate women's experiences and describe various contextual factors that render women vulnerable to human rights violations, are useful, effective and appropriate for educating women around their health rights. Thus this study:

1. brings new knowledge to the fore and contributes to work currently developing in the field of human rights as there does not seem to be much literature using qualitative research methods for health as a human right, as indicated in Chapter 3.
2. illustrates that women's views are shaped and determined by their personal histories, socio-economic backgrounds and experiences which have a significant influence on their perceptions and impact on their awareness levels, understanding and practice of health rights.
3. demonstrates that learning is contextual and is best understood through an analysis of women's real life situations by identifying the importance of the intersection between the vulnerabilities associated with being a woman and those created, enabled and facilitated by the broader context that render women vulnerable to infringement of their rights.
4. illuminates factors which inhibit or facilitate vulnerable women's awareness, understanding and practice of their health rights within a civil society context by showcasing the barriers and opportunities in relation to health rights.
5. showcases the successes and challenges these women encounter when trying to learn about (become aware, understand) or access (practice) their rights to health within the communities they come from, TWC and public healthcare contexts.
6. indicates a gap in current health rights research by highlighting the importance of community informers and the need to build a firm knowledge base in relation to health rights within communities as people trust others who share similar contexts.

7. managed to offer new insights in terms of the ambiguity of sites of learning, by highlighting how, where and what women learn and the impact this learning has on their awareness, understanding and practices particularly within public healthcare institutions which are important health 'rites' sites.
8. identifies the successes of the TWC programme, lessons to improve practice and strategies which are most effective in overcoming obstacles and facilitating health rights by advocating that TWC and programmes such as is planned by the UCT Health and Human Rights Unit should draw on adult education methodologies and approaches which include a range of formal, non-formal and informal methods, ultimately aimed at enabling vulnerable groups to understand and exercise their rights and facilitators of learning such as public healthcare professionals to understand and perform their duties within a human rights framework, which would be more effective in overcoming obstacles to rights to health.
9. illustrates London's (2004) view that health rights education should provide knowledge which encourage women to negotiate their health rights as build individual and collective women's agency to claim rights to health. The findings are consistent with London's argument that utilising a human rights framework is more suited to addressing vulnerable women's health inequalities than traditional approaches to health and healthcare

The study concludes that exploring the context within which women learn about and practice health rights will enhance our understanding of the gap between knowledge, awareness creation, understanding and practice in relation to health rights. In light of the findings of this study, I hope that efforts at health rights education and prevention of violations will prove more successful, given our enhanced understanding of the health rights context in South Africa.

4. RECOMMENDATIONS FOR FURTHER RESEARCH

The scope of the study was limited to women within TWC. This study therefore recommends and encourages further research to explore the following:

- other potential factors that are creating and maintaining the gap between awareness, understanding and practice of health rights;

- the socio-economic context of not only women and health rights, but other vulnerable groups in relation to human rights more broadly within South Africa; and
- the numerous facets inherent in any context that shape and restrict vulnerable groups from asserting their health rights.

Hopefully this exploration can provide new ideas and be of value to those working in diverse fields. More importantly may it add value to those working in the field of health, human rights and adult education with the view to strengthening efforts to protect and support poor women, who are a key resource in building and maintaining their communities' health.

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TWC consists of women belonging to a diverse range of organisations, companies and networks that come together to promote a culture of equity and women's rights around a programme of action that aims to:

- encourage a respect for women's rights and for women amongst all members of society
- orientate and equip women to meet some of the challenges of the 21st century
- expose women of all ages to a wide range of opportunities
- showcase innovative women-led projects and programmes
- celebrate women's achievements; and
- foster ongoing collaboration between various stakeholders

TWC promotes, lobbies and advocates for women's issues in a variety of contexts. They happen in all kinds of spaces e.g. community centres, health clubs, corporate lunch-rooms, wellness centres, schools and in members' homes. Using TWC's format, women across socio-economic and cultural divides can begin their own circle or join an existing circle.

The Women's Circle Experiences

TWC's exchanges and programmes are stepping-stones on a path to knowledge, discovery and action:

- Collaboration, sharing experiences, and learning from one another
- Learn, grow and take concrete steps to enhance women's lives and become the women we want to be
- Uncover new perspectives that have relevance in women's lives
- Develop strong ties with other women and share in each other's successes and challenges
- Listen to the experiences of others and be heard with respect and compassion
- Reflect on circumstances of women's lives; and
- Enjoy the opportunity to escape to a replenishing space

Use tools provided by Circle programmes to create and recognise possibilities, ignite positive movement, and generate desired results in women's lives



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